Premature deaths of vulnerable people due to poor quality care

Emergency nurses can learn from a report on treatment of patients with learning disabilities, says Daniel Allen

HENRY WAS taken into his local emergency department (ED) one morning with bleeding from his nose and mouth. The doctors and nurses were convinced he had had a seizure but his mother and sister knew otherwise. They told staff they suspected a brain haemorrhage or stroke, but were ignored until a scan proved them right and a nurse was sent to inform them.

‘They were very nice to us then,’ Henry’s sister says. ‘Of course it was a haemorrhage. All she could say to us was that she was sorry.’

Henry’s story is told in a report from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD). The document and the anonymised case studies it contains are, like the Winterbourne View scandal, an indictment of how some care services treat vulnerable people.

The report grew out of Mencap’s Death by Indifference report, which describes how ‘institutional discrimination’ had contributed to the deaths of six people with learning disabilities in NHS care.

In response to the Mencap publication, an inquiry established by the Department of Health and led by Sir Jonathan Michael found ‘a high likelihood’ that avoidable deaths had occurred and recommended that CIPOLD should be established.

The CIPOLD researchers, led by the University of Bristol, reviewed the deaths over a two-year period of 233 adults and 14 children with learning disabilities, and those of 58 people without learning disabilities who had received care in five primary care trusts. Those with learning disabilities were found to have died, on average, 16 years earlier than those without.

Emergency care staff will note from the report that delays in investigating, diagnosing and treating illnesses were more common among people with learning disabilities and, as was the case with Henry, their families and carers had problems being heard.

Jolt into action

Jim Blair, consultant learning disability nurse at St George’s Healthcare NHS Trust and senior learning disabilities lecturer at Kingston University and St George’s, University of London, says the CIPOLD report is ‘hard to ignore’.

‘It is a thorough piece of work and the evidence for what they are postulating is clear,’ he says. As such, he hopes the study will prove to be the ‘jolt into action’ needed to ensure better care for people with learning disabilities by mainstream health services.

Many people with learning disabilities find hospitals frightening, Mr Blair says, often because they have had poor experiences of them, and so emergency care staff must be especially careful not to miss potentially life-threatening illnesses.

This need for care is illustrated by the story of Robert, which, like that of Henry, is told in the CIPOLD report.

Robert lived in a care home and, one weekend, staff found he was ill. They called the out-of-hours doctor who sent him to an ED, but information that he may have aspirated food and fluids was not passed on.

Robert underwent electrocardiography, but no chest X-ray or blood tests were taken and he was sent home. His condition deteriorated over the weekend, despite two visits from the out-of-hours doctor. On the Monday, his GP was called and Robert returned to hospital, where he was diagnosed with ‘severe’ pneumonia.

The CIPOLD report says an earlier diagnosis of pneumonia might have prevented his premature death.

Lead author Pauline Heslop says that, among people with learning disabilities, early death is unlikely to be due to lifestyle problems. ‘The cause of their premature deaths appears to be a failure to provide NHS care based on need. People with learning disabilities are not diagnosed and treated to the same extent as other people. These are shocking findings and must serve as a wake-up call.’

A failure to provide care equitably may have legal implications and the CIPOLD review raises concerns about failures of some staff to adhere to the Mental Capacity Act 2005.

Mr Blair describes the act as the ‘single best piece of legislation in relation to people who lack the ability to make decisions for themselves’.

Compliance is not optional, he says, but should be integral to how people with learning disabilities are treated, and emergency care nurses who fail to comply with it could find themselves held to account.

As the Nursing and Midwifery Council’s professional code states, nurses and midwives ‘must be aware of the legislation regarding mental capacity, ensuring that people who lack capacity remain at the centre of decision making and are fully safeguarded’.
Hospital care of people with learning disabilities can also be compromised by poor adherence to national guidelines about decisions not to attempt cardiopulmonary resuscitation (DNACPR) and by inadequate record-keeping.

The CIPOLD study states that fully documented DNACPRs were sometimes missing and suggests that DNACPRs may have been made simply because the people concerned had learning disabilities.

Safeguarding procedures

Chair of the RCN Emergency Care Association Janet Youd says that some ED nurses find caring for people with learning disabilities difficult, not least because of the diversity of their requirements.

She says: 'Emergency department nurses must have appropriate training and support to provide appropriate care for all vulnerable people, including children, older adults and those with mental health needs.

Not least, they should have a working knowledge of how local safeguarding procedures apply. Some departments employ specialist staff to advise others on the specific care needs of vulnerable adults and that kind of service should be commended.'

Mr Blair estimates that, on average, five inpatients with learning disabilities are seen in his hospital each day. He urges emergency care staff to look for signs and symptoms when treating such patients.

'If you think there might be something there, do more. Always look for a biological reason for why something has changed for that person,' he says.

'Emergency nurses should also remember the knowledge of patients’ carers and families,’ he says.

'Emergency services will get better only if we recognise that we are not the experts, they are, and we have to engage with them better.’

Daniel Allen is a freelance writer

Staff should take opportunities to identify and help trafficking victims

Emergency nurses should check whether patients have long-term multiple injuries, or are withdrawn or submissive, and seek evidence of self-harm, poor nutrition and mental or physical trauma. Nurses should also look out for patients who book late for maternity care or appear to move house frequently, and for those who give vague and inconsistent explanations of where they live, work or go to school.

Vulnerable-adult training

The guide advises staff on how to respond to these signs without putting patients in greater danger and what to do if they suspect that any of the people they are treating are under the age of 18.

Senior lecturer in emergency care at University of Wolverhampton Jim Bethel says: 'Most emergency department nurses receive vulnerable-adult training that focuses on elder abuse or abuse of those with learning disabilities, and may not think of these otherwise-healthy, young adults as being at risk of trafficking. It is not something that many have encountered.’

Last year, 1,186 potentially trafficked people were identified through the UK’s victim support framework, the National Referral Mechanism, a figure 25 per cent higher than in 2011. It is likely, however, that many more victims of trafficking are unrecognised.

Emergency nurse practitioner at East Sussex Healthcare NHS Trust and Emergency Care Association committee member Helen Watts, who works near many of England’s south-coast ports, has experience of caring for people who have, or are suspected of having, been trafficked.

Referring to the guide she says: 'I used to rely on the contacts I had to try to sort it out, but this tool will make it much easier and more streamlined for staff.'

Erin Dean is a freelance writer

Guide for healthcare professionals explains how to recognise signs of sexual exploitation among patients. Erin Dean reports

EACH YEAR, many hundreds of vulnerable people are brought into, or moved around, the UK to be exploited sexually or forced to work. These adults and children are the victims of force and deception, and what has been described as a form of slavery.

Opportunities to assist such people arise when they seek health care. To help emergency nurses and other healthcare staff tackle the problem, the Department of Health and Platform 51, formerly the Young Women’s Christian Association, have published advice on identifying and supporting those affected.

The guide, which is accompanied by an e-learning programme, explains that the victims of trafficking can include men as well as women and children, and that people are targeted for many different reasons, including sexual exploitation, domestic servitude, forced labour, criminal activity and organ harvesting.

The guide, called Identifying and Supporting Victims of Human Trafficking, urges nurses to act even if they only suspect something is wrong, for example if a patient has an inconsistent story or has a particular pattern of symptoms.

Patients who have been trafficked often present to emergency departments only when seriously ill or injured, often with problems that have been left untreated.

Find out more

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities report is available at www.bris.ac.uk/cipold

Find out more

The Department of Health and Platform 51 guide can be accessed at tinyurl.com/bnjrnss