

Case: 201001305, Ayrshire and Arran NHS Board
Sector: health
Subject: clinical treatment; diagnosis
Outcome: some upheld, recommendations

Summary

Mr C complained about the care and treatment that his 17-year-old nephew (Mr A) received from the board before his death from sudden unexpected death in epilepsy (SUDEP).

Mr A had had a suspected seizure and had seen a consultant at the board's 'first seizure clinic'. The consultant said that Mr A might have had a seizure, but needed more information. He provided Mr A with his contact details and suggested that Mr A contact him again after obtaining a phone number for a witness to the event, so that the consultant could speak to them about it. Mr C said that Mr A was not aware of the significance of not obtaining a phone number for this person. He complained that after Mr A's appointment there was no proactive follow-up by the first seizure clinic.

Our medical adviser said that it is not standard practice to provide follow-up appointments following a first seizure clinic, as in many cases it will be unnecessary. Treatment is not given if there is no immediate reason to believe that another event will happen. The patient should contact his or her GP if any subsequent suspicious event occurs. Follow-up and treatment will start if considered appropriate. In Mr A's case, the consultant tried to obtain a first-hand witness account to help him decide on this, but could not do so. We, therefore, found that the consultant's actions were reasonable.

Mr A was subsequently admitted to hospital after collapsing. Guidance from the Scottish Intercollegiate Guidelines Network (SIGN) on epilepsy (SIGN 70) says that the diagnosis of epilepsy should be made by a neurologist or other epilepsy specialist. Mr A was given a provisional diagnosis of epilepsy by a general physician at the hospital, referred to a neurologist, then discharged. Mr C complained that the board failed to involve Mr A's parents in discussions about his diagnosis, treatment and advice before he was discharged.

Our medical adviser said that once over the age of 12, the law assumes that a person can make their own decisions about their health care unless there is evidence to suggest they cannot. Health workers are not usually allowed to tell such a patient's parents anything unless the patient has agreed to this. Mr A was aged 17 at the time. Unless the board had evidence to suggest that he could not make his own decisions about his health care, they were not required to involve his parents in discussions about his diagnosis, treatment and advice. Mr C also complained that Mr A was discharged from hospital with no verbal or printed information about epilepsy. He said that no individual or personal assessment was undertaken of Mr A's circumstances and no information was provided about SUDEP.

In general, patients should be fully informed about the risk of any condition and its treatment. Although death from SUDEP is rare, most patients should be given information about it at some point soon after a diagnosis of epilepsy has been made. This will help patients to understand the issue and put it in perspective. However, detailed information about epilepsy and the risk of SUDEP should be provided as part of comprehensive counselling about risks and prevention. This should be provided by or arranged by neurologists after a definitive diagnosis of epilepsy has been made. Mr A had not seen a neurologist.

Mr C complained that the board had delayed in arranging an appointment for Mr A with a neurologist. The appointment arranged for Mr A was some 17 weeks after he was discharged from hospital. Mr A died before the appointment. Although we did not uphold Mr C's other complaints, we upheld this one as we found the delay unacceptable. Our medical adviser pointed out, however, that the risk of SUDEP cannot be eliminated and it is not possible to say that an earlier appointment at the neurology clinic would have prevented Mr A's death.

Recommendations

We recommended that the board:

- issue an apology to Mr A's parents for the delay in arranging an appointment for him with a neurological consultant; and
- take steps to ensure that patients who have been given a provisional diagnosis of epilepsy are seen by specialists as soon as possible so that a definitive diagnosis can be made and, where appropriate, detailed and specific information can be given.