

SPSO decision report

Case: 201604485, Ayrshire and Arran NHS Board
Sector: health
Subject: clinical treatment / diagnosis
Decision: some upheld, recommendations

Summary

Mr C complained about the care and treatment provided to his late wife (Mrs A). Mrs A had amyloidosis (a condition caused by abnormal deposits of a protein called amyloid around tissues and organs in the body) and Mr C felt that the diagnostic process for this was slow. Mr C had concerns that biopsies undertaken by the board were found to be negative for amyloidosis, but were later found to be positive when tested at the UK's National Amyloidosis Centre. We took independent advice from a consultant physician, a cardiologist, and a pathologist. We did not find that there were any unreasonable delays in determining that Mrs A had amyloidosis. The advice we received was that it was reasonable that the National Amyloidosis Centre was able to make a diagnosis when the board did not, as the National Amyloidosis Centre is more experienced in the techniques for testing. We did not uphold this complaint.

Mr C also complained about failures in communication and failures in providing adequate support to Mrs A and her family during Mrs A's illness. We took independent advice from a consultant physician and found that the board's communication with the family throughout Mrs A's illness, and the support provided to Mrs A, was unreasonable and insufficient. We considered that a protocol for earlier involvement of specialist nurses, and consideration of how to access information from the National Amyloidosis Centre, would have minimised this issue. We made recommendations regarding this.

Finally, Mr C complained about the board's handling of his complaint. We found that the board had failed to meet deadlines and had failed to provide clear explanations to Mr C. We upheld this complaint. However, we found that the board had implemented a new complaints handling procedure since Mr C's complaints and so we did not make any recommendations around this issue.

Recommendations

What we asked the organisation to do in this case:

- Apologise to Mr C for failing to communicate with the family properly during Mrs A's illness, for failing to provide Mrs A with adequate support and for failing to handle Mr C's complaints about Mrs A's treatment reasonably.

What we said should change to put things right in future:

- There should be a protocol for how to involve specialist nurses in the care of patients with very rare conditions, and where to get specialised information and support.
- The board should consider how they could access information and support from the National Amyloidosis Centre to provide to patients.

We have asked the organisation to provide us with evidence that they have implemented the recommendations we have made on this case by the deadline we set.