

Case: 201001310, Fife NHS Board
Sector: health
Subject: clinical treatment / diagnosis
Outcome: some upheld, recommendations

Summary

Mrs C complained about the care and treatment provided to her late father, Mr A. Mr A was diagnosed with myelodysplasia and acute myeloid leukaemia. He was admitted to hospital and treated with chemotherapy. He also agreed to take part in the clinical trial of a new drug and signed the relevant consent form. After he started treatment with the trial drug mylotarg, Mr A developed gastrointestinal bleeding and fever. An ultrasound scan showed that he was suffering from veno-occlusive disease (an inflammatory condition of blood vessels in the liver). He deteriorated further, suffered multiple-organ failure and died. A post mortem established that the cause of death was acute myeloid leukaemia and its complications. Mrs C complained that Mr A had not been properly warned about the risk of developing veno-occlusive disease, that pain relief was not effective and that the board failed to communicate adequately. Our investigation found that the board did not specifically discuss with Mr A the risk of developing venal-occlusive disease from the drug trial. However, the risk was small and the information sheet provided to him before he took part in the trial referred to the risk, so we did not uphold this complaint. We did, however, uphold Mrs C's complaint about failures in the end of life care provided to Mr A in that the board failed to manage his pain in a reasonable way (although we recognised the difficulties they faced in doing so) or to properly communicate with Mrs C and her family.

Recommendations

We recommend that Fife NHS Board:

- ensure staff record discussion with patients when they are obtaining consent for treatment;
- review its procedures in line with 'Living and Dying Well' with particular reference to pain relief and communication;
- ensure that staff document in patients' medical records their communication with relatives and carers, in line with the guidelines; and
- apologise to Mrs C for the failures identified.