

SPSO decision report



Case: 202407182, Lothian NHS Board - Acute Services Division
Sector: Health
Subject: Clinical treatment / diagnosis
Decision: some upheld, recommendations

Summary

C complained about the care and treatment provided to their late spouse (A). A had primary sclerosing cholangitis (PSC, a chronic disease of the liver) and was under specialist supervision due to the increased risk of cholangiocarcinoma (CCA, cancer of the bile duct). An MRI scan identified a lesion in A's liver. A's case was discussed at multi-disciplinary team (MDT) meetings and further imaging and tests were carried out. This included a CA 19-9 test (a test to measure the amount of this protein in the blood). A was diagnosed with cancer a few weeks later.

A planned to undergo surgery but this was postponed after a scan showed the cancer had spread to A's liver. Further tests and imaging confirmed that surgery was no longer an option and A died around seven months later. C complained that the board did not undertake CA 19-9 tests within a reasonable timescale. They also complained about the communication around A's diagnosis and the conclusion that there was no curative surgical option for A.

We took independent advice from a consultant hepatologist (specialist in the liver, gallbladder, bile ducts, and pancreas). We found that there are no clinical guidelines which demand the carrying out of a CA 19-9 test or mandate its timescale. Therefore, we did not uphold this part of C's complaint.

In relation to communication, we found that A was informed of their cancer diagnosis at an arranged clinic appointment which took place around a week after the MDT meeting. This indicated that the diagnosis was treated as an urgent priority and communicated to A within a reasonable timescale. However, we found that it should have been made clear to A from the beginning that there was only a minimal chance of curative surgery being effective. Following postponement of A's surgery, investigations should have been undertaken quickly and the situation clearly explained to A. On balance, we upheld this part of C's complaint.

Recommendations

What we asked the organisation to do in this case:

- Apologise to C that the board did not communicate clearly the implications of changes to decisions about surgery. The apology should meet the standards set out in the SPSO guidelines on apology available at www.spsso.org.uk/meaningful-apologies.

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

- Patients are made aware of the risk of developing the different types of cancers when PSC is suspected or diagnosed. Patients are made aware that potential for management decisions in relation to their care and treatment can be changed at the last minute, and what the likely consequences of such changes can be – particularly in the case of cancellation of planned curative surgery. All relevant communications about the patient's diagnosis and treatment are documented in the patient's clinical records and letters.

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.