SPSO decision report

Case: **202103737, Lothian NHS Board - Acute Division**
Sector: Health
Subject: Clinical treatment / diagnosis
Decision: some upheld, recommendations

Summary

C complained about the care and treatment provided to their child (A). A developed facial weakness, which was initially diagnosed and treated as Bell's Palsy (temporary weakness or lack of movement affecting one side of the face). A's condition did not improve and MRI scans revealed a mass. It was considered this was likely a vestibular schwannoma (a rare, non-cancerous tumour) and follow-up in three months was arranged.

A later attended hospital with bleeding from the ear. C suspected this was related to the tumour but doctors treated A for an ear infection. A developed further ear symptoms and attended hospital again. Further scans showed significant tumour growth, requiring surgical debulking (removing as much of the tumour as possible). A's diagnosis was revised as para-meningeal rhabdomyosarcoma (a rare and aggressive form of cancer). A was treated with chemotherapy but they continued to deteriorate and died within a few months of this diagnosis.

C complained that the board's decision not to remove A's tumour when it was first detected was unreasonable. We took independent advice from four advisers: a paediatric neurologist (specialist in the diagnosis and treatment of disorders of the nervous system), a paediatric emergency medicine consultant, a paediatric neurosurgeon (specialist in surgery on the nervous system, especially the brain and spinal cord) and a paediatric oncologist (specialist in the diagnosis and treatment of cancer).

We found that there was inadequate documentation of the risks or benefits to A of performing a biopsy or resection of the tumour when it was initially detected. However, we considered that surgically it would not have been possible to carry out a full resection and that the risks of trying to obtain a biopsy in the specific circumstances were too high. We concluded that the decision not to remove the tumour when it was first detected was reasonable. Therefore, we did not uphold this part of C's complaint.

C also complained that the board's assessment of A's condition when they attended A&E was unreasonable. We found that the provisional diagnosis and management plan were reasonable, given the information available to the doctors at that time. Therefore, we did not uphold this part of C's complaint. We acknowledged that C had voiced their concerns that the appearance of A's ear related to the tumour, and noted the board had confirmed learning in terms of listening to parents' concerns.

Finally, C complained that there was an unreasonable delay in the board diagnosing A's condition. We took into account a number of factors including the fact that A's condition developed around the start of the COVID-19 pandemic, when services were severely restricted and face-to-face meetings were prevented from taking place. We found a number of shortcomings in A's care and treatment: insufficient record-keeping regarding the risks/benefits of resection or biopsy, failure to communicate clearly with A's family, the disputed position about whether it was reasonable to adopt a clear working diagnosis of schwannoma, the lack of opportunity of a second opinion, the delay in appointing the neurology referral, and a delay in writing to the GP following the initial multi-disciplinary team meeting. We considered that, taken together, these shortcomings were sufficient to have led to a delay in reaching an accurate diagnosis and upheld this part of C's complaint. Although the complaint was upheld,

we acknowledged the advice from each specialism that earlier diagnosis would not have led to a different outcome.

Recommendations

What we asked the organisation to do in this case:

- Apologise to C for the failings identified. The apology should meet the standards set out in the SPSO guidelines on apology available at www.spso.org.uk/information-leaflets.

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

- Where treatment decisions are being made at multi-disciplinary meetings, there should be adequate documentation of consideration of the risks/benefits. There should also be evidence of discussion with family members in relation to diagnosis and management plan, where applicable. Where a patient appears to have a condition which is extremely rare, the patient records should reflect the differential diagnosis.

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.