

Intended for healthcare professionals

🗨️Rapid response to:

Practice A Patient's Journey

Lessons from patients' journeys

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Rapid Response:

Re: Lessons from patients' journeys

I was encouraged by Peter Lapsley's confirmation that Patient Journeys do indeed help doctors to reach the correct diagnosis more quickly, and wish to offer my own experience in the hope of furthering that purpose.

I had three head injuries between 1972 and 2003: an accident when I was driving a truck in 1972, a violent assault in 1985 when I had a basal skull fracture, and the third head injury in 2003. After this I began to suffer from right neck pain from spondylosis, dizziness when I turned my head, attacks of acute vertigo with vomiting (though these subsided), and aches and pains. To these symptoms were added tinnitus and deafness in my right ear, and headaches. In 2004 I was referred to a dizzy clinic, but with no improvement in my health. By 2006 I was still suffering all my previous symptoms, with the addition of pains in my face, and tingling and numbness in both hands. I was diagnosed with Menieres symptoms. My GP found hypothyroidism, which he diagnosed as primary, and prescribed thyroxin. At this point I started to wonder if my problems might stem from my pituitary gland. I had a private BUPA test that showed my TSH levels were borderline low. However, a short synacthen test that year showed no abnormalities.

In 2007, desperate that I was feeling no better, and now suffering from atrial fibrillation, chest discomfort, chronic fatigue and sleep problems, I approached an eminent endocrinologist privately, but neither he nor the endocrinology department at Manchester Royal Infirmary discovered what was wrong with me. In 2008, in fact, I was discharged from that hospital with a diagnosis of chronic fatigue syndrome and a letter that said "We have explained to Mr Barker that there are no signs of an underlying endocrinological problem to explain his many symptoms . . . there may well be an element of psychosomatic or depressive problems . . . I am concerned that he may go on to undergo further investigation and medicalisation of his symptoms," and suggested cognitive behavioural therapy.

Now at the end of my tether after four years of dizziness, I changed my GP in order to be referred privately to Dr Tara Kearney, consultant endocrinologist at Salford Royal Hospital. How I wish I could have been treated by her from the beginning. Here at last, in 2008, I made two discoveries. One was that around a third of head injuries cause pituitary problems [1], and the symptoms can include dizziness, tingling and numbness, headaches and chronic fatigue. The other was that the short synacthen test is not a reliable way to diagnose ACTH or growth hormone deficiency, as it misses about 40% of cases [2]. At last I was given the right tests – the glucagon stimulation test and the arginine test – which together showed that I was suffering from growth hormone deficiency and ACTH deficiency. Dr Kearney said of me, "he has certainly had conflicting opinions from several

endocrinologists, however I have checked several insulin stress tests and glucagon tests and I am certain that Mr Barker has evidence of pituitary dysfunction." At long last I began the appropriate treatment.

Earlier, one of my GPs and a consultant did say it "was all in my head," and this, sadly, turned out to be prophetic, though not in the way they meant.

I wish I could say that this was the end of my troubles, but I had been so long deprived of growth hormone that my abdomen had swollen and I developed divanication of the rectus sheath and below that an incisional hernia. I am still very ill. I feel that if only there had been more awareness of the considerable risk of pituitary failure after head injury, and the shortcomings of the short synacthen test, my whole story might have turned out differently. But it will be a comfort to me if my story alerts doctors and helps others to be diagnosed.

References

[1] Schneider HJ et al, Hypothalamopituitary Dysfunction Following Traumatic Brain Injury and Aneurysmal Subarachnoid Haemorrhage: A Systematic Review, 2007, JAMA <http://jama.jamanetwork.com/article.aspx?articleid=208915>

[2] Dorin RI, Diagnosis of Adrenal Insufficiency, 2003, Annals of Internal Medicine, <https://annals.org/article.aspx?articleid=716603> The MEDLINE database was searched from 1966 to 2002 for all English-language papers related to the diagnosis of adrenal insufficiency, and it was found that for diagnosing secondary adrenal insufficiency, the sensitivity of the short synacthen test was 57-61%.

Competing interests: No competing interests

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Edward Barker
Unemployed
ME Association
Manchester M40