

How doctors are failing to spot the brain injury that could be behind 30,000 cases of 'chronic fatigue'



MISDIAGNOSED: Christine Wrighton fought before her death for more tests after doctors said she

THOUSANDS of British patients suffering from chronic pain and fatigue could be misdiagnosed with psychological problems when they unknowingly have a type of brain damage.

Those people who complain of the symptoms are not given a series of blood tests that can pinpoint the problem, meaning the true cause is not spotted. Patients are then condemned to years of misery and ineffective therapies.

The major cause of the damage is head injury, which can be relatively mild. However, viruses, tumours and even animal bites can be a trigger.

The National Institute for Health and Care Excellence was considering including the condition – called post-traumatic hypopituitarism (PTHP) – in its most recent guidance to doctors on how to treat head injury.

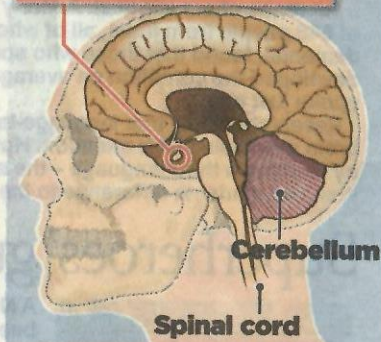
It would have meant patients who turned up at A&E departments or GP surgeries with head injuries would be warned that the symptoms of PTHP – which also include depression, obesity, high blood pressure, loss of libido and even infertility – could take years to emerge.

However, when the new recommendations were published in the spring, there was no mention of the problem. The decision has been condemned as ‘nonsensical’ by an expert who treats PTHP.

Currently, patients who present with tiredness and chronic pain are often told they have chronic fatigue syndrome (CFS), or fibromyalgia, once other physical causes have been ruled out. They are offered psychotherapy, exercise and antidepressants. However, these are currently found to be ineffective in up to 70 per cent of CFS cases.

Numerous studies have shown that

Pituitary gland is about the size of a pea



between 20 and 30 per cent of the 135,000 patients who suffer a serious head injury also experience damage to the pituitary gland, which is situated below the brain, behind the nasal cavity.

The gland produces vital hormones that govern many bodily functions, including growth and repair, the sleep-wake cycle and how we react to stress. If the pea-sized organ is damaged, it may stop producing one or more of the essential hormones, triggering the wide-ranging symptoms of hypopituitarism.

Studies suggest there could be between 18,000 and 30,000 cases in the UK each year.

Treatment involves lifelong hormone replacement therapy, which is said to be highly effective but costs up to £6,000 a year.

Professor Christopher Thompson, one of Britain's foremost experts on PTHP, says: ‘The overwhelming evidence from research studies carried out independently in a wide range of places, including the USA, Europe and Turkey, is that hypopituitarism occurs in up to 30 per cent of people who have survived moderate or severe traumatic brain injury. There is no debate.

‘However, the failure to make the right diagnosis after such injury means patients miss out on essential

treatment. That it's not included in the NICE guidelines [for treatment of head injury] is nonsensical.’

Serious head injury is defined as an injury causing unconsciousness for more than 15 minutes. However, some studies suggest even knocks that lead to a minor concussion, or repeated small impacts such as heading a football, may damage the pituitary gland.

PTHP sufferer Jill Mizen, 67, was misdiagnosed with CFS in 2006, having suffered from pain and blood pressure problems for almost 20 years. A former BT manager, she was advised to exercise more, but found her condition worsened.

During her illness, Jill was screened for deficiency in the hormone cortisol, a characteristic of hypopituitarism. However, the test – known as the short synacthen test (SST) – produced a normal result. ‘That was when I was told I had CFS,’ she says.

Yet SST misses two out of every five cases where the cause of cortisol deficiency is damage to the pituitary. In 2007, Jill came across a magazine article about Christine Wrighton, who was incorrectly diagnosed with CFS when in fact she was suffering from hypopituitarism.

‘Eventually, after huge persistence, Christine was able to pay privately for a test which the NHS would accept. This proved she had been right all along – her pituitary was faulty. Her story opened my eyes,’ says Jill.

Coincidentally, the two women were patients at the same hospital and struck up a friendship. Jill says: ‘Doctors believe Christine's hypopituitarism was caused by inflam-

mation – she suffered rheumatoid arthritis for 30 years. In 2005 she had a virus that wouldn't go, and the fatigue started then.’

Jill chose to be retested privately with the more reliable glucagon stimulation test, and was diagnosed as being deficient in cortisol and growth hormone. This proved she too had hypopituitarism.

Sadly, Christine died in July 2011 from complications related to her arthritis treatment, perhaps exacerbated by the fatigue she had suffered for so many years.

Dr John Newell Price, consultant endocrinologist at the Royal Hallamshire Hospital in Sheffield and chairman of the Pituitary Foundation Medical Committee, says: ‘A “pass” on an SST may not always mean cortisol deficiency is excluded.’ He recommends referral to an endocrinologist if symptoms persist, so that the glucagon test can be carried out.

Today, Jill wonders whether a concussion she suffered after jumping off a roundabout as a toddler could have caused the damage. Now she is having hormone therapy, her symptoms improved.

Last Christmas she once again had the energy to cook a proper family dinner and put on make-up. ‘It sounds silly,’ she says, ‘but I hadn't had the energy to do that for years.’

● For more information visit pituitary.org.uk or call 0845 450 0376.