

“NICE'S HEAD INJURY GUIDANCE WILL BE UPDATED MARCH 2023 AND WILL AT LAST INCLUDE HYPOPITUITARISM”

What is hypopituitarism?

The pituitary, a tiny gland below the brain, has an immense influence on our response to stress, our temperature control, our sleep, weight, mood, energy, memory, sex drive and clarity of thought. When it fails to work properly the effects can be life-wrecking. There are many pituitary disorders, but this leaflet focuses on what happens when the gland does not produce the hormones it should, in sufficient quantity. This is hypopituitarism. It happens after around a quarter of head injuries.

What are the symptoms?

The possible symptoms include chronic fatigue, impotence and infertility, weight gain, loss of muscle, brain fog, anxiety, depression, heart problems and osteoporosis.

Do people get diagnosed?

There is strong evidence that hypopituitarism is gravely underdiagnosed. BBC's 'Inside Health' aired an estimate of between half a million and a million undiagnosed sufferers in the UK today. Only around 13,000 people are correctly diagnosed annually. If the 'Inside Health' estimate is to be relied upon, the number of undiagnosed hypopituitarism patients in the average constituency will be between 7,500 and 15,000.

What diagnosis do they receive instead?

People with hypopituitarism have many disparate symptoms, and doctors tend to treat these symptoms, such as depression, heart trouble or osteoporosis, individually, without looking for the underlying cause. Patients who are not correctly diagnosed are often told that they have chronic fatigue syndrome, fibromyalgia or metabolic syndrome, which are all symptom clusters with no definitive diagnostic test or cure. (By contrast, the tests for hypopituitarism are precise, and treatment is simple and usually effective.)

Suicide Risk

Being misdiagnosed with a chronic fatigue illness deprives people of any hope of getting better. Hypopituitarism sufferers often complain that they look normal, so nobody understands or believes how terrible they feel. They are likely to be treated as malingerers and be socially isolated. The suicide risk is six-fold for those who are given the 'chronic fatigue syndrome' label. Similarly, the risk of suicide after head injury (a major cause of hypopituitarism) is between twice and four times the norm.



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The silence about the head injury and concussion risk

Around a quarter of head injuries result in pituitary damage. Even a single concussion can cause it. Yet for the past two decades NICE's head injury guidance has been silent on the risk and patients have not been warned, though next March the guidance will at last be updated to include hypopituitarism. Rugby players who suffer repeated concussions display the symptoms of hypopituitarism (growth hormone deficiency in particular) but they are not warned or screened.

The failure to test properly

Patients who self-diagnose from the internet and ask to be checked are, in the experience of Christopher Lane Trust, frequently denied the correct tests on mistaken grounds.

The failure to do the sums

The silence and reluctance to test may stem from the vast numbers of potential sufferers, the lifelong treatment necessary, and the expense of growth hormone. However, the cost-benefit case of treatment versus non-treatment may not factor in how NHS resources are squandered in responding to these patients, who constantly visit their GPs year after year, live on universal credit and other benefits until death, and how much would be saved if these patients were enabled to stop claiming benefits and contribute to society instead.

Failure to diagnose also exposes the patient to the risk of dying suddenly from adrenal crisis because hypoadrenalism (a common feature of hypopituitarism) has not been suspected, or from cardiovascular issues that have not been checked for, not to mention the risk of suicide. Every suicide costs the economy £1.67 million.

What needs to be done

- General practitioners need to be informed about hypopituitarism, particularly the significant risk after head injury including concussion. Their training should include this.
- Greater funding needs to be allocated to treating patients with hormone replacement, in particular growth hormone.
- Endocrinologists' misconceptions about testing for hypopituitarism, in particular growth hormone deficiency, need to be corrected.
- Patients discharged after head injury or concussion need full information about the risk of hypopituitarism, and a description of the symptoms.

Immediate next step

To form an all-party parliamentary group to work towards these objectives.

Research

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