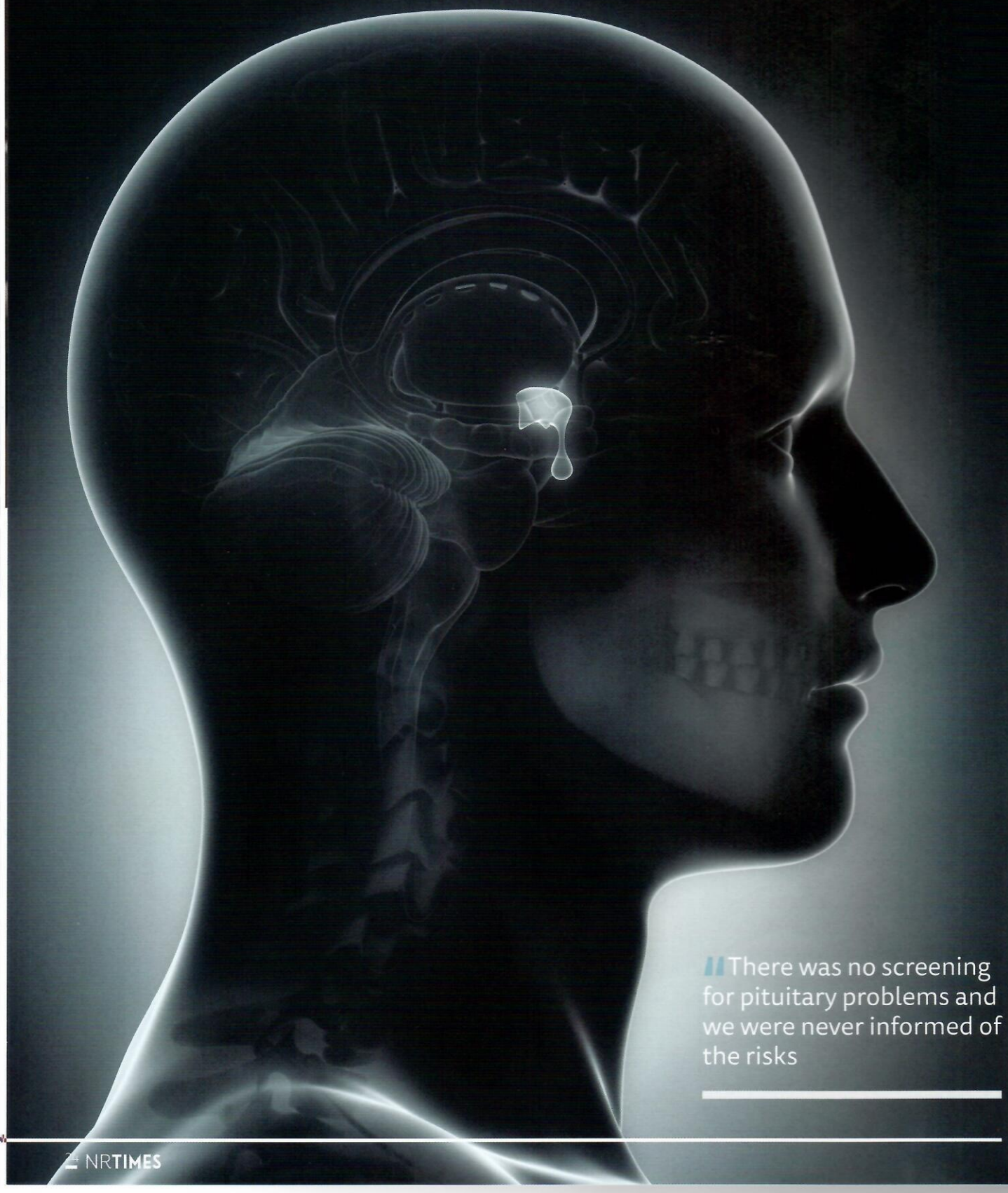


"There was no screening for pituitary problems and we were never informed of the risks

TRAGEDY, TRAUMA AND A MENTAL HEALTH COVER-UP

Personal tragedy set Joanna Lane on a mission to improve the diagnosis and treatment of hypopituitarism after traumatic brain injury. In the eight years since her son's suicide, her influence has been felt far and wide; but there's much more to be done, she tells Andrew Mernin

A knock on the door one sunny afternoon in 2008 changed Joanna Lane's life forever. It was the police with shattering news. Her son, 31-year-old Chris, had taken his own life. He was a "lovely boy" who loved tinkering on his piano, listening to Dido and hanging out with mum. He was considerate too – so much so that even in his final despairing hours, he was thinking of others. He sent pre-scheduled emails to alert the police and left his door unlocked so they could find his body.

His death devastated his family, friends and Skipton Building Society colleagues. It was also the start of his mother's fight to expose what she believes has been a decades-long mental health cover-up.

Eight years on, her endeavours have helped to bring the issue of hypopituitarism after brain injury to the fore, forcing healthcare decision-makers in various fields to rethink their approach to the condition.

Chris sustained a head injury when he fell out of a tree at age seven. He suffered skull fractures and spent a week in a coma. But undetected by doctors was the damage to his pituitary gland that would eventually cause devastating problems in later life.

"After his fall there was no screening for pituitary problems and we were never informed of the long-term risks. As we left hospital, a nurse did say in passing that his pituitary gland could be damaged, but when he grew up normally afterwards we stopped worrying."

As Chris got older, signs that Joanna now knows can be attributed to post-traumatic hypopituitarism (PTHP), emerged.

It wasn't until she put the jigsaw pieces of her son's life together in the aftermath of his death, that his silent suffering with the condition became clear. Hypopituitarism is the failure of the pituitary gland to adequately produce one or more hormones.

While no conclusive figure exists, most studies suggest around a third of people after traumatic brain injury (TBI) have at least temporary dysfunction of the pituitary gland.

It is well known as a cause of dwarfism in children, but is perhaps lesser known as a cause of depression and impotence; both of which affected Chris.

Joanna says: "When we went through his things we found letters from his ex-girlfriend which clearly implied they hadn't managed to have sex. I called her and found out they'd never managed it in the four years they were together. He'd never been able to get an erection but had refused to seek help.

"There were also bouts of depression. When he was doing his A-Levels and we were nagging him to revise he got mad and disappeared for three days. The stress got too much for him, which may have been a sign of a deficiency in the hormones which control stress. There were two similar occasions, including one when he suddenly left his job and drove up to Edinburgh with the intention of committing suicide.

That was three years before he died. We made a swift appointment with a psychiatrist and he was only offered counselling. We weren't told about the tripled risk of suicide after head injury.

"I don't think he ever told anyone about his impotence and his condition was never investigated further. I guess this was a missed opportunity.

"Remembering his head injury as a child, my sister and I then found a wealth of research linking damage to the pituitary gland with impotence and depression." >

> "I felt so angry to be treated like a little person that could be squashed by a big powerful organisation

She later discovered that a military hospital in Surrey was screening all head injury patients routinely for PTHP. "I then learned that this practice had been extended to the Queen Elizabeth Hospital in Birmingham, which is the first port of call for the wounded.

"This information meant I could ask why soldiers were screened while civilians weren't even warned."

A bigger challenge in Joanna's fight for change came when she took on the might of the National Institute for Health and Care Excellence (NICE). She argued that PTHP should be included in NICE's head injury guidelines.

NICE said the guidelines covered acute stage only, and that hypopituitarism takes months to develop, so therefore had no place in the guidance.

Joanna was backed up by significant evidence of hypopituitary problems in the immediate aftermath of TBI. As pituitary specialist Chris Thompson, professor of endocrinology at Beaumont Hospital, Dublin, wrote in an email to her in 2014: "It has been known since 1969 that 35% of patients surviving 12 hours after TBI have evidence of infarction of the pituitary. Infarction is cell death due to lack of blood supply. This was reinforced in 2007 by data which showed that there was no sign of infarction in 12 patients who died at the scene of TBI, but in 43% of patients who died within the first seven days, and who were studied at post-mortem.

"Our own data has shown that 30% of patients studied at 7-14 days post TBI have evidence of subnormal pituitary function and more recently, a more comprehensive daily assessment of 100 patients with TBI showed that 80% had subnormal cortisol levels at some state during hospital admission."

Despite her efforts, and support from experts like Chris Thompson, Joanna hit a brick wall as her bid for legal aid to support the case was rejected.

The legal aid agency said in a letter: "From the information provided, hypopituitarism is not something which is diagnosable within the early stages of a head injury and as such I cannot see that it falls within the remit of this guidance."

That was two years ago and NICE's guidelines have not changed since.

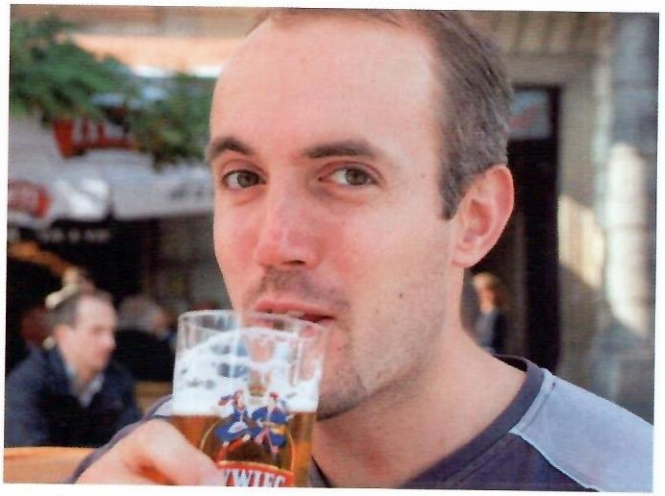
The organisation was unable to tell us about any plans to change them in the future, when contacted by NR Times. In the meantime, Joanna hopes her new book *Mother of a Suicide: Fighting for the Truth* will raise awareness of PTHP and encourage healthcare authorities to do more to recognise and screen for the condition.

"I felt so angry to be treated like a little person that could be squashed by a big powerful organisation like NICE so I thought I'd write a book giving the evidence so that people could make up their own minds.

"The words just flowed out when I was writing about Chris, but the other stuff about my fight to change the system, was a lot harder, trawling through several years worth of emails and research."

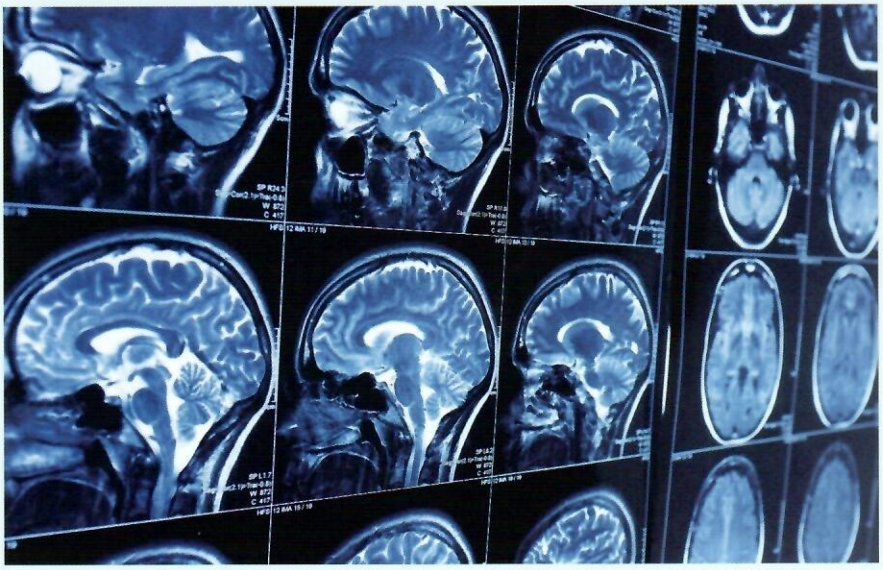
Given her relentless work over the last eight years in highlighting the hidden threat of hypopituitarism, she certainly had plenty of source material for her book.

If buoyant early sales are anything to go by, it may well have the desired effect and help more people in future avoid the tragedy that befell Chris Lane and his family.



Hypopituitarism in focus

It is roughly estimated that a third of people after traumatic brain injury have at least temporary dysfunction of the pituitary gland. Often this lasts beyond the acute phase and will be a serious, but treatable, cause of unnecessary further disability.



The pituitary gland lies at the base of the brain and is connected to the brain by a small stalk with direct neural links to the hypothalamus. It is vulnerable and can be easily damaged in brain injury. It is divided into two parts - the anterior lobe and the posterior lobe. The anterior lobe is responsible for the production of growth hormone (GH), luteinising hormone (LH), follicle stimulating hormone (FSH), adrenocorticotropic hormone (ACTH), thyroid stimulating hormone (TSH) and prolactin.
Regulation of these hormones is largely under the control of the hypothalamus. The posterior pituitary gland produces arginine vasopressin (AVP) which has a key role in maintaining fluid balance in the body. It also produces oxytocin which stimulates uterine contraction during birth and ejection of milk during lactation. Growth hormone deficiency causes growth failure or slowing of growth in children. In adults it can cause decreased energy, increased fat and reduced muscle mass. Concerns should be raised if a child is beginning to show slowed growth after a TBI. In adults growth hormone deficiency can be easily overlooked as the symptoms of decreased energy and tiredness and increased weight are very common in any case after brain injury.

HORMONES

FSH-LH – Deficiency in the production of these hormones can cause problems with the menstrual cycle, loss of libido, hot flushes, dyspareunia (pain during sexual intercourse) and infertility in women. In men it is often associated with loss of libido, impaired sexual function as well as mood impairment, loss of facial, scrotal or trunk hair and decrease in muscle bulk and easy fatigue. Once again these are problems that are quite common after brain injury and diagnosis is not always obvious.

ACTH - Chronic ACTH deficiency is also associated with fatigue, anorexia, weight loss and sometimes other metabolic complications such as low sodium and sugar levels. In children it can present with delayed puberty and failure to thrive. In more severe cases ACTH deficiency can be associated with vascular collapse, particularly during superimposed illness.

TSH is the hormone that stimulates the thyroid gland to produce thyroxine. Individuals with TSH deficiency show the symptoms of hypothyroidism. These symptoms can include tiredness, coldness, constipation, hair loss, dry skin, hoarseness, general lethargy including slowing of 'cognition', weight gain and low blood pressure.

Prolactin - Fortunately there is no clinical syndrome that is known to be associated with prolactin deficiency.

TESTING / TREATMENT

In terms of anterior pituitary function, individuals should be referred to a local endocrine department if there are concerns about pituitary function. Simple blood tests of the hormones are not usually adequate as the pituitary gland needs to be 'dynamically' tested. Provocative tests stimulate hormone release either indirectly (by, for example, injecting a small dose of insulin) or directly by injecting synthetically manufactured peptides (synacthen).

Other tests are possible such as a glucagon stimulation test or an oral glucose tolerance test. This is clearly a specialist area and it is important to emphasise that simply taking blood to measure the hormones is not adequate. Treatment for all the above conditions is simply by the administration of the appropriate hormones and thus it is important to recognise pituitary function as some, if not all, of the unpleasant symptoms can be readily alleviated.

In terms of posterior pituitary function, AVP deficiency leads to cranial diabetes insipidus which is not to be confused with a 'sugar' diabetes mellitus. This condition causes the passage of large volumes of dilute urine (often more than three litres per day). This can obviously lead to dehydration and severe thirst. It is a disorder well recognised and quite common in the acute phase of TBI but can extend for many months or years after the injury. Diagnosis is usually quite straightforward by measuring urine osmolality before and after administration of the AVP analogue called desmopressin. However endocrine referral is generally needed for diagnosis and long-term follow up.

The treatment is usually straightforward and is by administration of desmopressin. There is no known role for oxytocin production in men but in woman oxytocin is probably necessary for the regulation of lactation and birth and reproductive behaviour but relatively little seems to be known about the effect of lack of production.

SCREENING

Ideally everyone after a TBI should have pituitary function screening but this is unlikely to happen and indeed has serious resource implications for the NHS. The problem is that many of the symptoms of pituitary dysfunction overlap with symptoms that are common in any case after TBI. Fatigue is a particular example. This is extremely common after brain injury but also very common in pituitary dysfunction. At the moment there are no clear guidelines. Pituitary dysfunction is more common after severe brain injury and after basal skull fracture so perhaps those people should be screened. Those who develop diabetes insipidus in the acute phase should also be followed up and screened. ●

Information provided by the UK Acquired Brain Injury Forum (UKABIF).

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