Head injury: how nurses can improve awareness of a long-term risk

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The results of pituitary gland damage can emerge years after the trauma that caused it, but nurses can be effective in early detection

- Post-traumatic hypopituitarism (PTHP) can occur years after head injury
- Mother campaigning to raise awareness wants hospitals to alert head injury patients to the issue on discharge
- Nurses have a critical role in early detection of pituitary gland damage as they are often in a prime position to spot the signs



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When Joanna Lane's son Christopher took his own life in 2008 at the age of 31, she had no idea why he had been so depressed.

It was only when she found a box containing letters between he and his girlfriend that Ms Lane discovered her son had been unable to have sex.

Damage caused by trauma that occured years earlier



Joanna Lane

She looked into possible causes of his impotence and, after research, believed everything pointed to the cause being an injury to his pituitary gland years earlier. When he was seven he had fallen on his head, leaving him in a coma for several days.

The pituitary gland may be small in size, but its role is significant, controlling as it does the functions of other glands including the thyroid and adrenal, as well as the ovaries and testicles.

The results of damage to the pituitary – a bean-shaped gland located below the brain, behind the nasal cavity – can emerge years and perhaps decades after the trauma that caused it. In men, it can compromise testosterone production and the ability to sustain normal sexual function.

Hypopituitarism linked to head injury is known as post-traumatic hypopituitarism (PTHP). According to a 2015 <u>South Korean study</u>, between 30% and 70% of people with brain injury have symptoms of reduced secretion from the pituitary gland.

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Treatment options if post-traumatic hypopituitarism is detected

Ms Lane and her husband John were devastated by what her research suggested. Their son's lack of testosterone could have been detected by a simple blood test and might then have been easily treatable with hormone replacement therapy.

They believe if they had known their son had PTHP, he would probably still be alive today.

Galvanised by the knowledge she gained, Ms Lane embarked on a campaign to raise awareness among healthcare professionals.

Signs and symptoms of hypopituitarism

Each of these symptoms occurs in response to the loss of one or more of the hormones produced by the pituitary. Typical symptoms are:

- Excessive tiredness and decreased energy
- Muscle weakness
- Reduced body hair
- Irregular periods (oligomenorrhoea) or loss of normal menstrual function (amenorrhoea)
- Impotence
- Reduced fertility
- Decrease in sex drive
- Weight gain
- · Increased sensitivity to cold
- Constipation
- Dry skin
- Pale appearance
- Low blood pressure and dizziness on standing (postural hypotension)
- Headaches
- Vision disturbance
- · Diabetes insipidus

Source: The Pituitary Foundation



Christopher Lane with his mother

'It is great to have nurses on board'

The National Institute for Health and Care Excellence (NICE) has been a focus of much of Ms Lane's lobbying – she wanted to ensure that clinicians give PTHP due consideration.

Ms Lane approached a number of organisations, including the RCN, in late 2019 asking them to lobby NICE to update its guidance as a matter of urgency.

The college was the first one on her list to request an 'exceptional update,' declaring the issue an 'important matter' in December.

Ms Lane says: 'The RCN is absolutely marvellous for doing this.

'Nurses are critical to the early detection of pituitary gland damage as they are often in a prime position to spot the signs'

Joanna Lane, post-traumatic hypopituitarism awareness campaigner

'People suffering undiagnosed pituitary gland damage will have a lot to be grateful to them for, for starting the ball rolling – a lot of other organisations including <u>Headway</u>, the brain injury charity, wrote to NICE expressing the same wishes.

'It is great to have nurses on board – they are critical to the early detection of pituitary gland damage as they are often in a prime position to spot the signs.'

NICE now says: 'An extension of the guideline scope to include... the identification and management of post-head injury hypopituitarism is needed.'

It plans to amend guidance in 2021 – it was last reviewed in September 2019 following a paper by the British Neurotrauma Group on the screening and management of pituitary dysfunction following traumatic brain injury.

An RCN spokesperson said: 'This is a welcome step and something the RCN asked for. It will help improve care for patients following head injury.'

Hypopituitarism: causes other than head injury

- · Tumours (usually benign) that press on the pituitary gland
- Infections such as meningitis
- · Severe bleeding in the brain or during childbirth
- Chemotherapy and radiotherapy

Source: Hormone Health Network

Raising awareness of PTHP among healthcare professionals

Ms Lane's battle to increase awareness of PTHP, particularly among healthcare professionals, began in earnest in the year following her son's death. 'It was the one thing I could do, that I knew he would have wanted me to do,' she says. 'It was the only good that could come from his death.'

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The former English teacher has devoted all her spare time to this cause. She has generated much national media coverage, and persuaded Labour MP Valerie Vaz to table an early day motion – a way of drawing attention to an issue – in the House of Commons to prompt the change to NICE guidance for patients with head injury that is now pending.

She even managed to get PTHP written into a storyline for the BBC1 hospital drama Holby City.

In addition, she has written to every clinical commissioning body in the UK urging them to recognise PTHP as a condition linked to head injury.

This has raised awareness significantly among GPs – 136 out of 178 clinical commissioning groups she contacted have said they will either include PTHP in their bulletin for GPs or in their training.

PTHP: an under-diagnosed complication



Neuroscience nurse Catheryne

Waterhouse researched post-traumatic hypopituitarism (PTHP) after being contacted by Ms Lane, and wrote about it in a 2013 <u>paper for the British</u> Journal of Neuroscience Nursing.

In her paper, she calls PTHP an 'under-diagnosed complication'.

'A simple blood test can confirm the deficiencies caused by this damage'

Ms Waterhouse, who works for Sheffield Teaching Hospitals NHS Foundation Trust and for the Headway charity, says: 'The problem is that the symptoms of hypopituitarism can be the same as for so many other things. A simple blood test can confirm the hormone deficiencies caused by pituitary gland damage, but it's not happening enough.

'Nurses working in the field of neuro-rehab should push for baseline hormone testing for PTHP, but the responsibility lies with the patient's GP, and there needs to be more campaigning to improve their awareness.'

Informing patients about what to look out for following head injury

Ms Lane wants a warning added to hospital discharge letters issued to patients recovering from a head injury, advising them to be aware of the symptoms of PTHP.

She estimates that only one NHS organisation specifically warns all patients with head injury when they are discharged about the possibility of having or developing PTHP in the future.



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She has been calling for patients with head injuries to be screened for pituitary gland damage, after she discovered through a freedom of

information request that military veterans who have had head injuries are regularly screened for PTHP.

Although increased awareness among healthcare professionals would come too late for Joanna Lane and her family, she says of her efforts to improve recognition and treatment of PTHP: 'It has taken time for NICE to accept that a guideline revision was badly needed. Thankfully, from next year, it will make a huge difference to the quality of many lives.'

Sources of help and support

If you or someone you know has been affected by the issues in this article, call the Samaritans on **116 123**. Their helpline is open 24 hours a day, seven days a week.

Nurse or nursing student members of the RCN who are experiencing a mental health problems can contact the RCN's confidential counselling service on **0345 772 6100**.

Lynne Wallis is a health writer

Further information

- British Neurotrauma Group
- Headway, the brain injury association
- Hormone Health Network
- NICE guidance on head injury
- Pituitary Foundation
- Post-traumatic hypopituitarism (PTHP): an under-diagnosed complication (British Journal of Neuroscience Nursing)