

'I'm back': Journeys to diagnosis, symptoms, and change with treatment in NPH

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- People with NPH frequently experience **changes in identity, mood, motivation and social functioning** as well as gait, cognition and continence
- Improvement in symptoms after **shunting** is often experienced as a **profound return of self**.
- Clinicians diagnosing and treating NPH should **ask about symptoms outside the classic triad, such as low mood and apathy**.

INTRODUCTION

- Normal pressure hydrocephalus (NPH) is a potentially **treatable neurological syndrome** characterised by excess cerebrospinal fluid (CSF) in the brain's ventricles¹.

NPH classic symptom triad

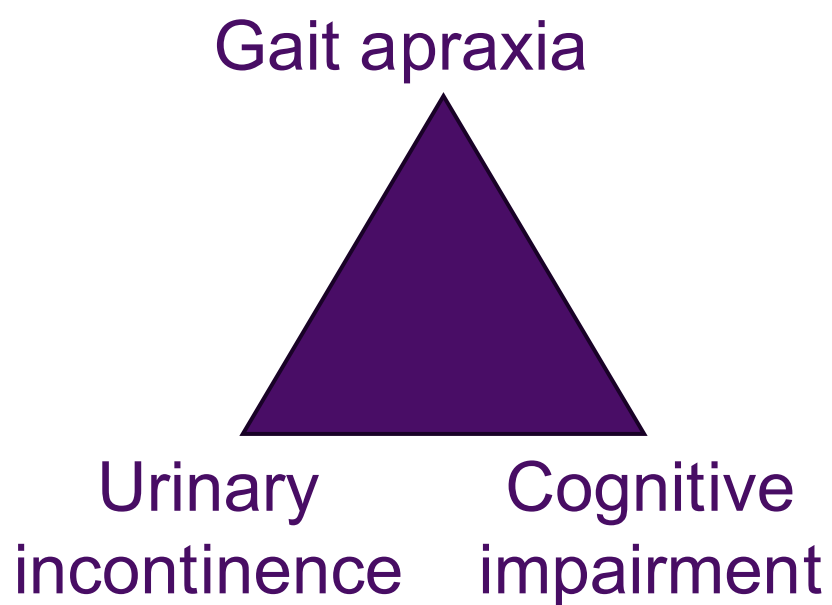


Fig 1. NPH symptoms: the classic triad^{1,2,3}

- Diagnosis of NPH is challenging and it may be **underdiagnosed and undertreated**^{4,5,6}.
- There is **skepticism regarding the effectiveness of NPH treatment** – surgical shunting – despite growing evidence that shunting improves gait^{7,8}.

OBJECTIVES

- To explore the **experience of**:
- 1) **Symptoms throughout NPH**, their impact, and responses to treatment.
 - 2) **Facilitators and barriers** to NPH diagnosis and treatment.

METHODS

- We purposively recruited, for demographic diversity, people diagnosed and treated for NPH and family members, through a UK hydrocephalus charity.
- We conducted **semi-structured interviews** until theoretical sufficiency.
- We analysed using reflexive thematic analysis
- We discussed and interpreted the results with people with lived experience.

RESULTS

- We carried out 14 semi-structured interviews.
- Most people with NPH were male (n=9) and white (n=13).
- Mean age 73 (range 63-80).

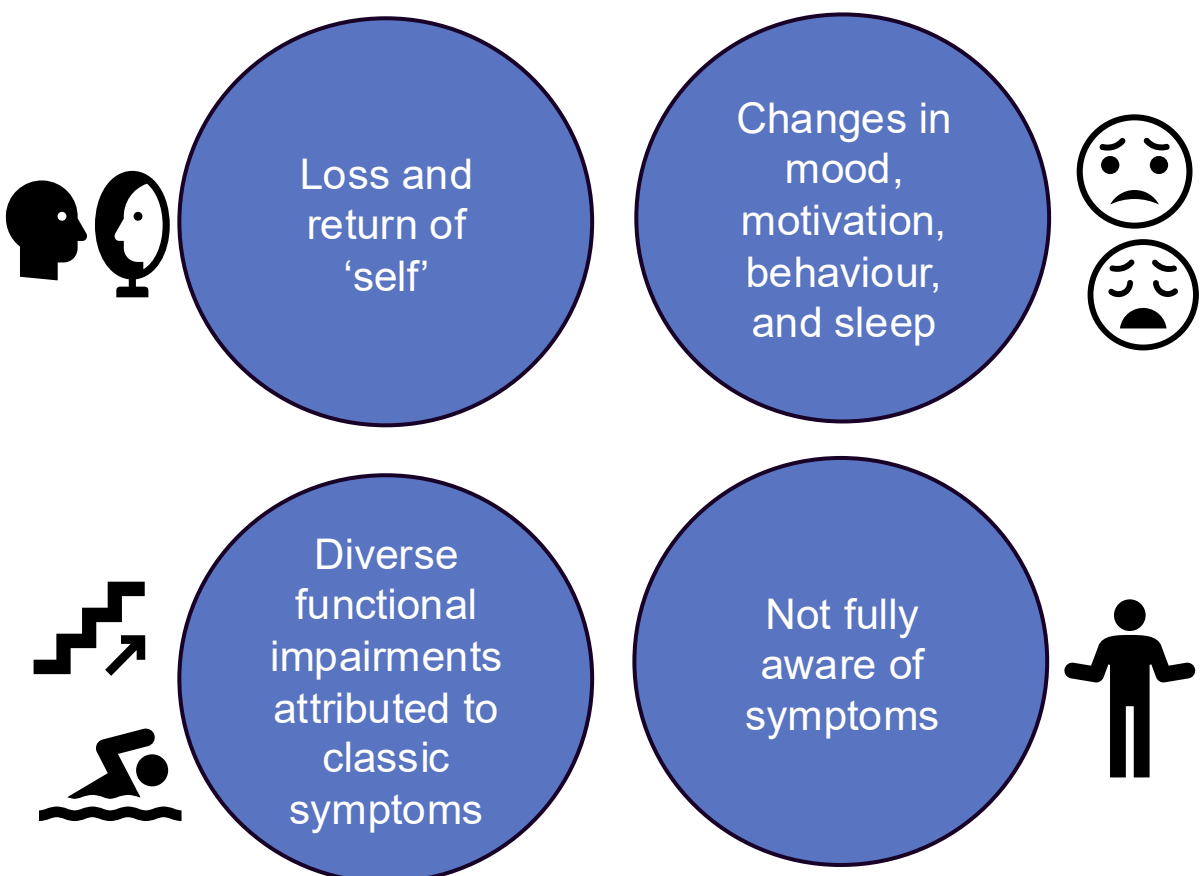
THEMES

Experiences and consequences of NPH symptoms

My granddaughter said, "Grandpa, **you're back**".

I'm back. I'm back to the mum that they used to see.

All those happy, sharp edges of life...I wasn't having the **strong emotional reactions**.

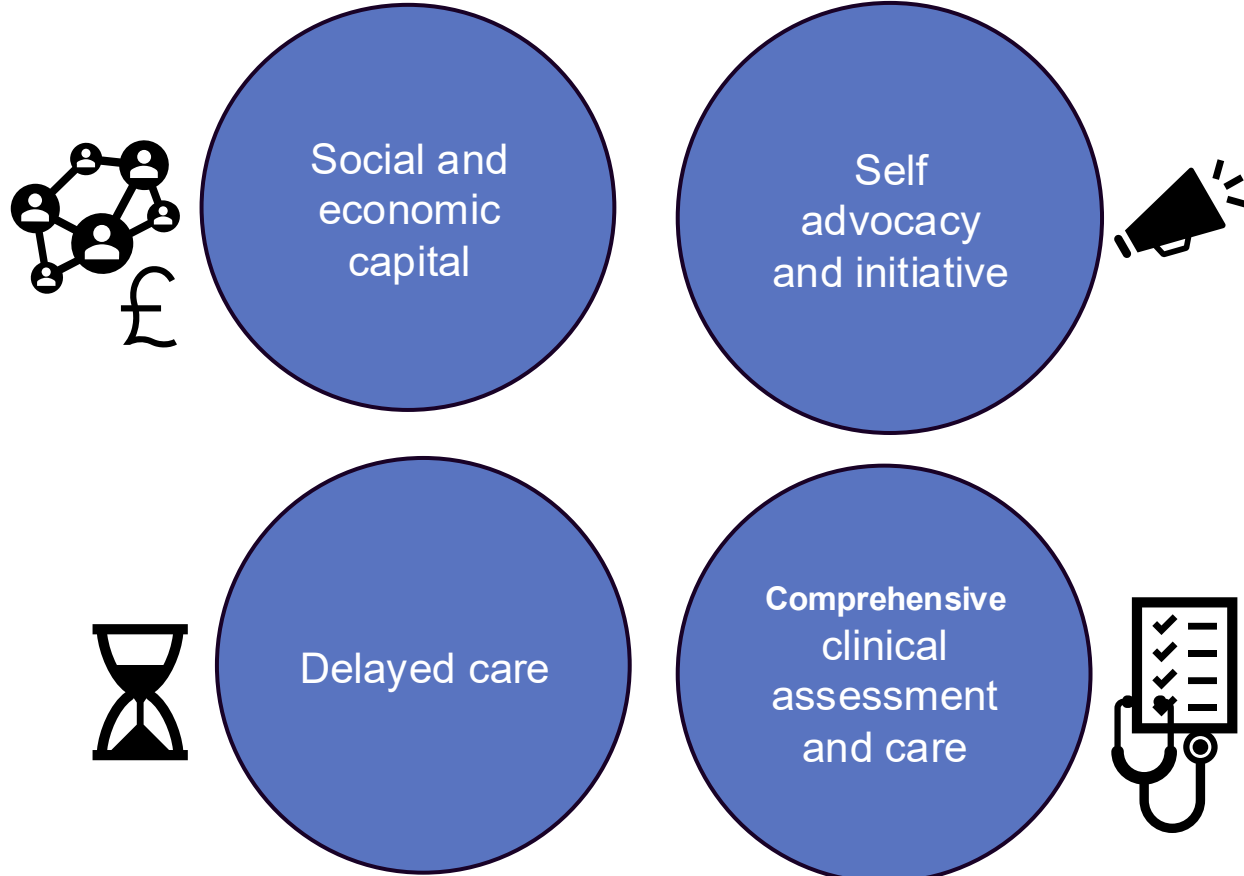


My favourite activity of swimming, I just couldn't **make the arms and the legs work together**.

It wasn't until I went into hospital and **did the first cognitive tests that I thought "Oh my God, I don't know what I'm doing" ... a while after [treatment] was the only time I was conscious of, oh, I must've been in a very bad way**.

Facilitators and barriers to diagnosis and treatment

I know about how **secretaries can help... if I hadn't known that... we could still be waiting now**.

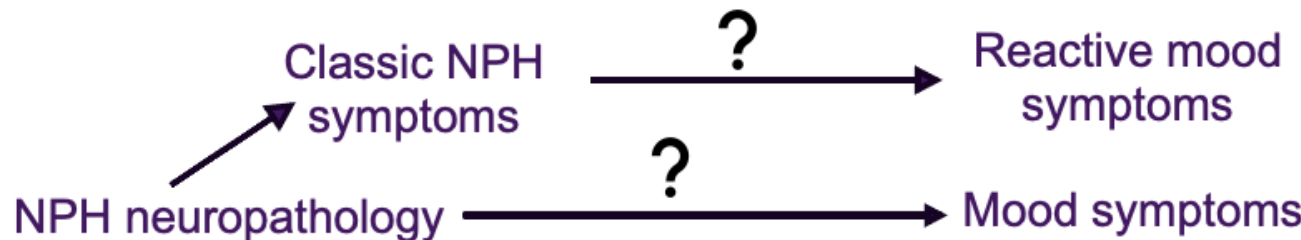


It's this **waiting, you know, and seeing them getting worse all the time**.

The **physiotherapist that was linked to the team, particularly, he was very good**.

DISCUSSION

- Improvement in the range of symptoms after shunting, including non-classic symptoms such as apathy, is often experienced as a **return of the self**.
- This is not classically captured in trials of shunting⁸.
- Difficulty navigating healthcare systems may be partially because NPH can cause cognitive impairment.



CLINICAL IMPLICATIONS

- Clinicians diagnosing and treating NPH should ask about non-classic symptoms, such as personality change, apathy, mood, sleepiness.

REFERENCES

1) Piccini C, Bracco L, Amaducci L. Treatable and reversible dementias: an update. J Neurol Sci. 1998 Jan 153(2):172-81.
2)Belessiotis-Richards C et al. Neuropsychiatric Features in Patients With Idiopathic Normal Pressure Hydrocephalus. Neurol Clin Pract. 2026 Apr;16(2):e200586.
3)Hu Q et al. Patient-reported Symptoms in Idiopathic Normal Pressure Hydrocephalus (P2-3.008). Neurology. 2024 Apr 9:102
4) Williams MA, Reikin NR. Diagnosis and management of idiopathic normal-pressure hydrocephalus. Neurol Clin Pract. 2013 Oct;3(5):375-85.
5) Brean A, Elide PK. Prevalence of probable idiopathic normal pressure hydrocephalus in a Norwegian population. Acta Neurol Scand. 2008 Jul;118(1):48-53.
6)Fernández-Méndez R et al. Current epidemiology of cerebrospinal fluid shunt surgery in the UK and Ireland (2004-2013). J Neurol Neurosurg Psychiatry. 2019 Jul;90(7):747-547
7)Saper CB. The Emperor has no clothes. Ann Neurol. 2016;79(2):165-68
8) Pearce RKB et al. Shunting for idiopathic normal pressure hydrocephalus. Cochrane Library. 2024 Aug 6:2024(8).