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## Implications for Practice: Why signposting patients to the Pituitary Foundation matters

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**Foundation matters** 

Many pituitary conditions impact on day-to-day functioning both pre and post-treatment. Patients feel generally unwell and struggle with fatigue and sleep disruption, thus exacerbating memory and concentration problems and mood swings<sup>3</sup>. These symptoms can be difficult to comprehend and live with for both the patients and their families, not least because they fluctuate but also because HCPs, especially post-treatment, can offer no explanation as to why they are happening. Often presenting initially with generally vague symptoms, the process of diagnosis can be long and arduous, with patients seeing their GP multiple times<sup>1</sup>. Being told that you have a tumour, even a benign one, is frightening for patients, carrying as it does, strong overtones of cancer. Unsurprisingly then, pituitary conditions have been found to have a large negative impact on quality of life<sup>3</sup>.

With an over-burdened NHS, the third sector is increasingly important in assisting and empowering patients to manage their health conditions, especially the psychosocial aspects that HCPs often neither recognise nor address; not because

Living with a pituitary condition

they are unaware or do not care, but because they simply do not have time and/or believe that they do not have the necessary skills<sup>4</sup>. Founded in 1994, The Pituitary Foundation's main objective is to provide information and support to help individuals with pituitary conditions to manage the day-to-day issues they may face. The Foundation offers many resources to its members, including access to emotional and psychological support for their diagnosis. The Foundation's resources are evidence-based and designed by experienced researchers and HCPs in the field. The Foundation also offers support through patient conferences and local support groups as well as telephone helplines. One of the strengths of The Foundation is the variety of ways it delivers information and support, with local support groups being especially important, providing a vital boost to individuals with a long-term health condition.

Patients value the Pituitary Foundation as a vital source of support and information when trying to make sense of their condition. Rather than being referred patients often stumble upon The Foundation during internet searches when newly diagnosed and many people with pituitary conditions throughout the UK are still not members of The Foundation. <sup>2</sup> Most GPs will have several patients with pituitary problems on their list. Why not do a search and recommend the Pituitary Foundation to them?

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## References

- Forrest H, Norman A, Jackson S & Percuklievska N (2017) Patient Satisfaction Survey. Final report for the Pituitary Foundation.
- Underwood A, Norman A, Jackson S (2019) Pituitary conditions: Importance
  of geography and the Pituitary Foundation in patient support. Br J Community
  Nurs, 24 (9): 1-7
- 3. Andela, C. D., Lobatto, D. J., Pereira, A. M., et al (2018). How non-functioning pituitary adenomas can affect health-related quality of life: a conceptual model and literature review. *Pituitary*, *21*(2), 208-216.
- Bessell A, Dures E, Semple C & Jackson S (2012) The need to address appearance-related distress across clinical conditions: How can healthcare teams support patients? B J Nurs, 21 (19), pp1138-1143