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► To cite this version:

Thomas Cuny, Rachel Reynaud, Pascal Barat, Blandine Gatta-Cherifi. Craniopharyngioma: medico-social support for optimised care. *The Lancet. Diabetes & Endocrinology*, 2023, 11 (10), pp.717-718. 10.1016/s2213-8587(23)00260-7. hal-04370676

HAL Id: hal-04370676

<https://hal.science/hal-04370676v1>

Submitted on 18 Jan 2024

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Craniopharyngioma: medico-social support for optimised care

Craniopharyngioma represents the archetypal pathology requiring multidisciplinary and transitional approaches, and for which the post-treatment management is as important, if not more so, than the treatment of the tumour itself.¹ Recent progress made in the understanding of the pathogenesis of craniopharyngioma, especially at the molecular level,² will pave the way for new therapeutic paradigms in coming years.³

In *The Lancet Diabetes & Endocrinology*, a consortium of experts from the UK produced national guidelines⁴ of the utmost importance for the management of paediatric craniopharyngioma. The French Endocrine Society and French Society for Paediatric Endocrinology & Diabetes have also joined forces to work on a similar reference document with the aim of discussing paediatric and adult craniopharyngiomas. This document is scheduled to be presented during the national congress of the French Endocrine Society (Marseille, France, Oct 4–7, 2023).

The recommendations issued in the paper by Hoong-Wei Gan and colleagues⁴ are valuable aids in optimising the management of children and young people with craniopharyngiomas. While we recognise the excellence of the proposed consensus, we feel that some points deserve to be given greater prominence. These include measures that need to be taken at the level of the health-care system to facilitate the integration of children and young people in educational and extracurricular environments. It is well known (and specified as recommendation 4.11 in the guidelines by Gan and colleagues⁴) that, because of multiple neurocognitive deficits

related to craniopharyngioma treatments, the impact on quality of life is substantial in children and their families, especially if the disease is diagnosed after the age of 6 years.⁵ The public authorities, through their local branches, must offer children and young people with a craniopharyngioma support measures within dedicated medical and educational structures, in conjunction with the medical and paramedical teams working in pituitary tumour centres of excellence.⁶

Guidelines are also an opportunity to point out that the economic burden of a craniopharyngioma should systematically lead to measures to cover 100% of the medical costs incurred. This coverage would ensure access to care regardless of the means of the patient or their family. Whether patients with craniopharyngiomas benefit from specific support for a health condition, such as the UK Disability Living Allowance, could have been discussed in the guidelines by Gan and colleagues.⁴ According to the Equality Act 2010, access to school for children with disabilities should be permitted through reasonable adjustments and an education, health, and care needs assessment. Although similar measures currently exist in France, they are unfortunately not always well known by the medical community, which is why we think they should have been at least discussed in the guidelines.⁴

The aim of these measures is to coordinate and reassess the appropriateness of rehabilitative care to avoid overloading timetables and to determine the intensity and establish the chronology of care for all the problems identified. The priority is to maintain the child at home and integrate them into a mainstream school environment. The need for a school-life assistant should be systematically assessed.

These measures would help young patients and their relatives to manage in the best possible conditions the so-called invisible disabilities, which these patients often have. Similarly, we believe that, beyond standardised multidisciplinary management (including neurosurgeon, paediatrician, endocrinologist, radiotherapist, neuropsychologist, dietitian, and social assistant), patients suffering from craniopharyngiomas should be considered as having brain damage, all the more so after extensive and or repeated surgeries. Patients with brain damage (such as patients with traumatic brain injury) could benefit from specific care and support in a dedicated age-appropriate physical medicine and rehabilitation unit, particularly in the event of severe cognitive sequelae.

Long-term support must also include educational programmes provided by caregivers. These programmes have proved their effectiveness in patients with pituitary diseases, including in those with craniopharyngiomas.⁷ Such programmes should be systematically recommended in the global care of patients as they contribute to alleviating the burden of the disease. Eventually, substantial support for patients and their families should be represented by associations of patients, which contribute to the patient medico-social management in the long term.

We declare no competing interests.

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Published Online
September 5, 2023
[https://doi.org/10.1016/S2213-8587\(23\)00260-7](https://doi.org/10.1016/S2213-8587(23)00260-7)

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