We recommend rigorous dental hygiene and regular dental check-ups in cystinosis patients to monitor for gastrointestinal side effects. If hepatomegaly or splenomegaly is apparent, we suggest using ultrasound together with LFTs in collaboration with a GI specialist.

Typically, the signs/symptoms of the onset of muscle involvement in cystinosis are distal muscle weakness. Masticating and Swallowing Solids (TOMASS) difficulties and oral dysfunction tend to appear later. For intervertebral muscle involvement in cystinosis, we recommend spirometry tests and endocrinologist and urologist care. This care should be tailored throughout according to the individual patient's kidney function.

However, we acknowledge that the frequency at which each specialist is involved should be tailored to the needs of the patient. We recommend that nephrology care is initiated as soon as the diagnosis is confirmed. Onset of neurology involvement is dependent on the presence of cystinosis in the brain. Therefore, we recommend that a neurologist be involved in the care of patients with nephropathic cystinosis to prevent the development of other complications. In the juvenile form, they may become overt in later life. Following the development of neurology involvement, there are a number of parameters to consider when deciding whether to refer to a neurologist, including the presence of headache, seizures, and executive function deficits. The presence of any of these symptoms indicates an urgent need to refer for further evaluation.

For the juvenile form, we recommend that a neurologist be involved in the care of patients as early as possible. They should be involved in the care of patients with this rare disease. An additional eight international experts (the Extended Faculty, EF) were involved in the drafting and reviewing of the recommendations. The EF were recruited from various countries and the EF provided additional perspectives on the consensus recommendations. They provided additional expertise and knowledge in the field of cystinosis, and their input was invaluable in ensuring the quality and breadth of the recommendations.

Graphical Abstract

Keywords: Nephropathic cystinosis, cysteamine, metabolic diseases, adult nephrology, transition of care.
**DATA AVAILABILITY STATEMENT**

All data underlying this article are incorporated into the article and its supplementary information files. Supplementary recommendations and guidance for monitoring psychological well-being are detailed in Supplementary Table S1. The impact of motivational interviewing on adherence and symptom severity in adolescents is assessed in Supplementary Table S2.

**Contributor Information**

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**Ethics**

All procedures were conducted in accordance with the ethical standards of the Helsinki Declaration of 1975, as revised in 2008.

**Supplementary Material**

Supplementary recommendations and guidance for monitoring psychological well-being are detailed in Supplementary Table S1. The impact of motivational interviewing on adherence and symptom severity in adolescents is assessed in Supplementary Table S2.

**Conflict of Interest**

C.W. has received honoraria for lecturing and advisory services from Amicus, Idorsia, and Alexion. F.E. received personal fees from Recordati Rare Diseases, Alexion, and Idorsia. F.L. received personal fees from Idorsia and Alexion. All other authors declare no competing interests.

**Supplementary Information**

For supplementary information, please visit the supplementary information section of the journal's website.