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A call for better training in restless legs syndrome

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Published in:
Lancet Neurology

DOI:
[10.1016/S1474-4422\(21\)00244-1](https://doi.org/10.1016/S1474-4422(21)00244-1)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2021

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Deerenberg, C., Gould, J., & Andrews, R. (2021). A call for better training in restless legs syndrome. *Lancet Neurology*, 20(9), 700-701. [https://doi.org/10.1016/S1474-4422\(21\)00244-1](https://doi.org/10.1016/S1474-4422(21)00244-1)

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who died.² Between March 27, 2020, and Jan 8, 2021, the largest increase in excess mortality in England was observed in people with dementia, among whom mortality was eight times higher than before the pandemic.³

Although vaccination is leading to a so-called new normal phase of the pandemic, the scale of the dementia challenge is likely to increase substantially. The closure of many memory clinics, combined with social distancing measures and fear of infection, has led to a sharp decrease in referrals, with around 40 000 people waiting for a diagnosis across the UK at the time of writing. In March 2021, dementia was the leading cause of death in England.⁴

The wider dementia community needs to stand ready for this challenge. New ways of working must be implemented to maintain high quality care in a world where COVID-19 is endemic, including more flexible procedures for direct referrals and better telemedicine. A coordinated response across the clinical and research sectors is required.

The Dementia UK Ecosystem brings together leaders from the UK Dementia Research Institute, Dementias Platform UK, the National Institute for Health Research, the pharmaceutical industry, and funders to create a cohesive community, coordinating efforts to accelerate progress in tackling dementia.

This strength of will must be matched by support from the UK Government. Now, more than ever, is the time to invest in dementia research. COVID-19 has shown the world how science can tackle major health challenges, which should set an example to learn from. Members of Dementia UK Ecosystem have joined forces to coordinate research efforts and to strengthen collaborations between researchers across the preclinical and clinical sectors. We will work to streamline clinical trials and implement novel systems

to enable effective recruitment. This effort requires long-term funding commitment and increased investment in a field that remains considerably underfunded.⁵

The current UK Government declared dementia as a priority in their 2019 general election manifesto,⁶ with a promise to double research funding in a so-called moonshot effort to find treatments. People with dementia have been disproportionately affected by the pandemic, and the research sector has faced more than a year of severe disruption, thus now is the time to fulfil that promise. The pandemic will pass. Dementia will remain. This is not a problem we can wait to solve.

GL and BDS report support from the UK Dementia Research Institute (funded by the UK Medical Research Council, Alzheimer's Society and Alzheimer's Research UK) to facilitate Dementia UK Ecosystem discussions on topics relevant to this work. MR is the National Director for Dementia Research at the National Institute for Health Research (NIHR). JBR reports research grants from the NIHR, UK Medical Research Council, Wellcome Trust, PSP Association, Evelyn Trust, Alzheimer Research UK, and Parkinsons UK, unrelated to this work; has received consultancy fees from Astex, UCB, Biogen, WAVE, and SV Health unrelated to this work, and from Alzheimer Research UK, unrelated to this work; has provided expert witness reports in private medicolegal cases unrelated to this work; and is a non-remunerated Trustee of Guarantors of Brain, PSP Association, and Darwin College Cambridge.

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A call for better training in restless legs syndrome

Restless legs syndrome is a common neurological disease.¹ However, insufficient knowledge about restless legs syndrome among health professionals often leads to poor recognition, misdiagnosis, and flawed treatment, with their associated health-care and societal costs.^{2,3}

In the UK, for instance, guidelines for the treatment of restless legs syndrome list self-help advice and provide some patient information. These guidelines seem insufficient because by the time a patient seeks medical help symptoms are usually frequent and disruptive, and can severely affect not only the patient's sleep but also usual daytime activities. Patients often find it difficult to articulate their symptoms. Descriptions of the uncomfortable sensations that accompany the urge to move vary, but common phrases include: "like water running or insects crawling under my skin" and "like a wound up coil, but unable to unwind." Doctors should be alert to possible restless legs syndrome in individuals who use similar phrases or complain of nocturnal discomfort or sleep disruption.

Dopamine agonists, the most prescribed first-line pharmacological therapy, are associated with two major complications. The first is impulse control disorders, such as

For more on the Dementia UK Ecosystem see <https://ukdri.ac.uk/news-and-events/dementia-ecosystem-uk-action-through-alliance>

pathological gambling or shopping and hypersexuality, with devastating consequences.⁴ The second is augmentation, an increase in severity that can lead to the extension of symptoms to other body parts.⁵ With a prevalence of 6–12%, augmentation is the most common issue raised in forums of patients with restless legs syndrome; its risk increases with long-term treatment and high dopaminergic dosage. Most patients have to eventually reduce or stop their medication to resolve augmentation.⁵ This process involves little to no sleep for weeks and constant, intensified symptoms of restless legs syndrome.

In the UK, restless legs syndrome is not covered in the curriculum for either undergraduate or post-graduate training of medical doctors. The consequent lack of knowledge causes unnecessary disease burden.

Furthermore, many patients with restless legs syndrome with severe side-effects after long-term treatment report that their doctor had never heard of augmentation. The significant weekly influx of new people on patients' forums with similar stories and complaints support these observations.

Education and training of health professionals in restless legs syndrome would substantially improve recognition and treatment of this common disease and patients' quality of life, and thereby also reduce its economic impact.

CD, JG, and RA are patients with restless legs syndrome. We declare no competing interests.

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