



NEWS

Petition against “cruel” and “ridiculous” guidance on access to medicinal cannabis attracts 400 000 signatures

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The BMJ

The parents of severely epileptic children have launched a campaign to try to get the strict new guidelines for the provision of medicinal cannabis revised after some found that doctors were reluctant to prescribe the recently legalised medication.

In a letter to the *Times*, the families of 12 children said that they still faced the “cruel and ridiculous” prospect of being forced to go abroad for treatment, even though cannabis based medication has been made legal in the UK after an earlier campaign.^{1,2}

One of the signatories, Hannah Deacon, the mother of 6 year old Alfie Dingley, has gathered around 400 000 signatures on a new petition urging a review of the guidelines. She said that she had been unable to get a doctor to prescribe the medication because the guidance was so restrictive.³

Since launching the petition, however, she has clarified with NHS England that Alfie will continue to receive his medication on the NHS. But she urged others to sign the petition because “many hundreds of people still cannot get access to medical cannabis prescriptions as the guidelines remain unchanged.”

The Home Office announced last month that doctors would now be allowed to prescribe the medication after a review prompted by the high profile cases of Alfie Dingley and Billy Caldwell. But guidelines produced by the British Paediatric Neurology Association said that it should be used only as a “treatment of last resort” for children whose epilepsy has proved intractable to treatment with conventional epilepsy drugs; who have not responded to the ketogenic diet or for whom the diet is inappropriate; and who are not candidates for epilepsy surgery.⁴

The parents wrote in their joint letter to the *Times*: “We now face the stress and trauma of having to fundraise to undertake trips abroad to be able to access the very medical cannabis products that have just been made legal here, all the while caring for our extremely sick children. This outcome is as cruel as it is ridiculous.”

Finbar O’Callaghan, president of the British Paediatric Neurology Association and professor of paediatric neuroscience at the Institute of Child Health in London, told *The BMJ* that the only cannabis based medicine that had undergone clinical trials for use in children with epilepsy was Epidiolex, which was pure cannabidiol. The trials showed modest efficacy for that medication, but products containing tetrahydrocannabinol had not gone through controlled trials, he said.

“We were asked for evidence based guidance,” he said. “The guidelines have been through all the evidence and were developed after consultation with paediatric neurologists all around the country. There is just no good evidence that those products work or are safe, and that’s why we’re not recommending them. If trials are done to prove these products are both efficacious and safe, we will embrace them.”

The guidelines operate on an interim basis, with formal guidance expected to be issued by the National Institute for Health and Care Excellence by October 2019.

A spokesperson for NHS England said, “The new guidance will help individual medical professionals to use the available evidence to prescribe what is most effective for their patients and will not stop anybody getting the treatment they need. A second opinion service will give people access to a second clinical view if they disagree with their specialist’s recommended prescription.”

- 1 Torjesen I. Medical cannabis will be available on prescription in UK from autumn. *BMJ* 2018;362:k3290. 10.1136/bmj.k3290 30049690
- 2 Hawkes N. Cannabis based drugs should be rescheduled to make research and prescribing easier, says chief medical officer. *BMJ* 2018;362:k2957. 10.1136/bmj.k2957 29976556
- 3 Hurlley R. Medical cannabis: “restrictive” guidance lets patients down, say campaigners. *BMJ* 2018;363:k4654. 10.1136/bmj.k4654 30385431
- 4 British Paediatric Neurology Association. Guidance on the use of cannabis-based products for medicinal use in children and young people with epilepsy. 31 October 2018. https://www.bpna.org.uk/userfiles/BPNA_CBPM_Guidance_Oct2018.pdf

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