

## The Neurological Alliance Medicinal Cannabis Policy Position

This paper outlines The Neurological Alliance's position on medicinal cannabis. It has been formulated in consultation with The Neurological Alliance's member organisations. However, some of our individual member organisations have their own individual positions, with different nuances and areas of concern highlighted.

### Policy position

- We welcome the rescheduling of certain cannabis-based products for medicinal use, from Schedule 1 and into Schedule 2 of the Misuse of Drugs Regulations.
- Where there is strong evidence to support the benefits of cannabis-based products, we want to see more licensed treatments for people with neurological conditions, available on the NHS.
- The Neurological Alliance wants to see more clinical trials into cannabinoids, as this has the potential to lead to a greater range of licensed cannabis-based medicines, which would improve the range of safe and effective treatment options available to people with neurological conditions. We therefore welcome the current calls for cannabis-based medicinal research by the National Institute for Health Research.
- We want national data collection on prescribing of cannabis-based products for medicinal use in the NHS and private sector to be expedited, to monitor levels of uptake.
- We welcome the Department for Health and Social Care's working group on cannabis-based medicinal products but would like to see more representation of patient organisations, to help ensure appropriate patient access and to address issues relating to patients accessing illegal, unsafe forms of cannabis.
- We believe there may be a need for greater support and training for professionals in relation to the prescribing and use of cannabis based products, in order to ensure that patients who are likely to benefit are prescribed the medications.
- We believe that a concerted NHS information campaign is needed, to better inform people with neurological conditions about cannabis-based products, including safety and quality concerns, and their likelihood of being able to access cannabis-based medicines on the NHS.
- There is also a need for improved information about the 'artisanal' cannabis products legally available, but at present largely unregulated. Patients need to be clear that these products have not been manufactured under the same stringent conditions as pharmaceutical grade products.

People with neurological conditions already use forms of cannabis

There is anecdotal evidence that some people with neurological conditions are already using different forms of cannabis to help alleviate their symptoms. These include refractory seizures, pain and muscle spasticity. Different types of cannabis are used, including illegal forms such as smoked cannabis, and legal forms including some cannabis oils, available to buy as food supplements from health shops. "Medical cannabis" is a broad term for any sort of cannabis-based medicine used to relieve symptoms.<sup>1</sup> However, with unregulated products quality and dosage cannot be guaranteed.<sup>2</sup> Moreover, there's a possibility they will contain THC, a psychoactive compound which can affect brain functioning, causing changes in behaviour, mood and consciousness.<sup>3</sup> So, with such products, patient safety cannot be guaranteed. Moreover, many of these products contain >0.2% THC and are illegal to possess or supply.

There are few legal, guaranteed safe and effective, forms of cannabis available

There is also anecdotal evidence to suggest that people with neurological conditions would like access to legal forms of cannabis which are guaranteed to be safe and effective. But in order to be guaranteed to be safe and effective, cannabis-based medicines need to be underpinned by strong trial evidence. Cannabis-derived drugs are very different from cannabis that is available legally or illegally, in terms of the reliability of their content and purity; and cannabis-derived medications differ from CBD oils.<sup>4</sup> Unfortunately, at present there are few options available which meet these criteria. The main options include:

- Nabiximols (Sativex) is a cannabis-based medicine used to relieve muscle spasticity in people with MS who have not responded to other treatments. It is licensed in the UK, and available to patients on the NHS in Wales. But it is generally not available on the NHS in England. This is because the National Institute for Health and Care Excellence (NICE) does not recommend it as being a cost-effective treatment. However, it is provided in some specialist settings or via private prescription.<sup>5</sup>
- Epidiolex is a medicine used to treat refractory seizures in patients with epilepsy. It is not yet licensed in the UK but is currently going through the licensing system. It is now recommended as the default choice when considering prescription of a cannabis-based medicinal product to children with intractable epilepsy.<sup>6</sup> It can be prescribed for other conditions as a special.

Given the desire shared among many people with neurological conditions (or their parents/ carers) for access to legal, safe and effective forms of cannabis, to treat pain as well as seizures and muscle spasticity, the lack of viable options available is a clear area of concern. The Neurological Alliance wants to see more licensed treatments available to people with neurological conditions, available on the NHS.

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<sup>1</sup> [NHS information page on medical cannabis](#). Accessed 01/02/19.

<sup>2</sup> *ibid*

<sup>3</sup> MS Society [Cannabis and MS: The role of cannabis in treating MS Symptoms](#). July 2017. Accessed 01/02/19.

<sup>4</sup> Thomas RH, Cunningham MO Cannabis and epilepsy Practical Neurology 2018;18:465-471

<sup>5</sup> Association of British Neurologists [ABN Interim Guidelines December 2018: Use of cannabis-based products in neurology](#) Accessed 01/02/19

<sup>6</sup> British Paediatric Neurology Association [Guidance on the use of cannabis-based products for medicinal use in children and young people with epilepsy](#). October 2018.

More research, leading to clinic trials, is needed

Evidence now strongly suggests the efficacy of cannabidiols in treating some neurological symptoms. However, there remains a need for better understanding of how cannabidiols work, including safety and side effect concerns, in a wider range of symptoms and conditions. This includes the impact of drug interactions on safety and effectiveness. Further research should therefore be undertaken to improve knowledge and understanding of how different formulations of cannabinoids, in different forms, could benefit people with neurological conditions. The Neurological Alliance wants to see more clinical trials into cannabinoids, as this has the potential to lead to a greater range of licensed cannabis-based medicines, which would improve the range of safe and effective treatment options available to people with neurological conditions. We therefore welcome the current calls for cannabis-based medicinal research by the National Institute for Health Research.

Even where there are legal, safe, effective cannabis treatments, few are able to access them

In November 2018, the Government rescheduled certain cannabis-based products for medicinal use, moving them out of Schedule 1 and into Schedule 2 of the Misuse of Drugs Regulations (with the exception of synthetic cannabinoids). Moving cannabis-based products for medicinal use to Schedule 2 means those products can be prescribed medicinally where there is an unmet clinical need. The Neurological Alliance welcomes this change, on the basis that it gives another treatment option to those whose symptoms are not relieved by existing medications.

While clinical guidelines by NICE being prepared (due for publication Autumn 2019) NHS England asked the British Paediatric Neurology Association (BPNA) to develop clinical advice on the use of cannabis-based products for medicinal use in paediatric patients with certain forms of severe epilepsy. NHS England also asked the Royal College of Physicians (RCP) to develop guidance around prescribing of cannabis-based products for medicinal use in intractable chemotherapy induced nausea, vomiting and chronic pain. NHS England subsequently asked Association for British Neurologists to produce guidelines on the use of cannabis-based products in neurology, for people with very rare severe forms of epilepsy and adults with spasticity caused by multiple sclerosis.

Together with the Department for Health and Social Care's letter setting out expectations of what this regulatory change will mean in practice for clinicians working in the NHS and in private practice in England, the guidance for clinicians outlines specific criteria for the prescription of cannabis-based products. There is some concern in the neurology patient community that these interim guidelines may have been drawn too tightly, and that there are others who fall outside of the criteria/categories specified who may benefit, who may use alternative, unsafe forms of cannabis instead. Questions have also been raised about the lack of formal engagement with patient organisations in their formulation. Some concerns have also been expressed that patients who meet the criteria outlined in the guidelines are not being prescribed these products, as yet.

The Neurological Alliance wants national data collection on prescribing of cannabis-based products for medicinal use in the NHS and private sector to be expedited, to monitor levels of

uptake. We welcome the Department for Health and Social Care's working group on cannabis-based medicinal products but would like to see more representation of patient organisations, to help ensure appropriate patient access and to address issues relating to patients accessing illegal, unsafe forms of cannabis.

Given the specific criteria for prescribing cannabis-based products it is essential that there are no impediments to accessing these products for patients who do meet eligibility criteria.

Whether clinicians on the specialist register feel they have all the information and knowledge to be confident to prescribe remains to be seen. Anecdotal evidence suggests there may be a need for greater support and training, in order to ensure that clinicians are equipped to prescribe and confident about when to do so/not to do so, and that patients well placed to benefit are prescribed the medications. Similarly, while it is only clinicians on the specialist register who are in a position to be able to prescribe, others including specialist nurses, and GPs, are being asked about cannabis-based medicines by patients and have an important role in providing information and thereby guiding patients' expectations. The Neurological Alliance would like to see official bodies, such as the Royal Colleges/Health Education England or similar, to make an assessment of any training needs and make provision for this if/where it is found to be needed.

#### Patients are vulnerable, and need access to high quality information

Patients and their families who are desperate for effective treatments are necessarily in a vulnerable position. While the media has played an important role in bringing about the change in the law, the UK press reporting of CBD has evidenced some confusion. We note that "Artisanal CBD available on the high street has sometimes been conflated with highly effective medications that have strong trial evidence".<sup>7</sup> "Moreover, there are political and economic groups that support the legalisation of cannabis who will seek to exploit individual cases for the greater benefit of their cause".<sup>8</sup> Consequently, many patients are confused, or have high hopes of being prescribed cannabis-based medicines, when in reality they may be unlikely to benefit. This is clearly problematic in and of itself, but also due to the knock-on impact on health professionals, who are faced with numerous inquiries and disappointed patients.

The Neurological Alliance is of the view that a concerted NHS information campaign is needed, to better inform people with neurological conditions about cannabis-based products, including safety and quality concerns, and their likelihood of being able to access cannabis-based medicines on the NHS.

There is also a need for improved information about the 'artisanal' cannabis products legally available, but at present largely unregulated. Patients need to be clear that these products have not been manufactured under the same stringent conditions as pharmaceutical grade products, that the active ingredients may therefore vary, and that they may contain other impurities.

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<sup>7</sup> Thomas RH, Cunningham MO [Cannabis and epilepsy](#) Practical Neurology 2018;18:465-471

<sup>8</sup> Thomas RH, Cunningham MO Cannabis and epilepsy Practical Neurology 2018;18:465-471