

END OUR PAIN

A Patient's Guide to Accessing Medical Cannabis in the UK

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A note from the End Our Pain Campaign

Dear Supporter,

We wanted to share our thoughts with you on the current situation for access to medical cannabis. The movement to access medical cannabis has made incredible progress over the past few months. Since the recent high-profile cases there has been a monumental shift in government policy surrounding the medical and therapeutic benefits of cannabis.

Government often works slowly, so achieving change can often be a long drawn out and complicated process. But in this case, after decades of insistence from successive governments that cannabis has no medical benefit (and was therefore listed in Schedule 1), this government is now moving very quickly. The Home Secretary has now decided that some medical cannabis products will be moved out of Schedule 1. But exactly which products will be covered by this and how they will be regulated and prescribed is still to be decided. As a campaign, we want to see medical cannabis being available under prescription from GPs in the UK. And by medical cannabis, we mean the whole plant extract as long as it is manufactured to at least Good Manufacturing Practice (GMP). We are concerned that some advisors to the Government are pushing for a different outcome. They seem to want a limited subset of extractions from the plant, and for them to all be subject to the lengthy and costly licencing regime required of synthetic drugs. For us, this would be a poor outcome and risks making all the great progress of recent months feel like a false dawn.

In the meantime, the Government has set up an expert panel to assess applications for special licences to access medical cannabis products now. This guide is intended to help people who may be thinking of applying to the new panel, and to give some general background about medical cannabis.

We would encourage patients to advocate for their right to access medical cannabis. We know that for many families and patients this is the beginning of an incredibly important journey. We hope that the information we share can support you and help make sense of the many changes that have been announced over the last few months.

Best wishes,

End Our Pain

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A note from Hannah Deacon, Ambassador for End Our Pain

Dear Supporter,



Our journey was tough. Alfie was in hospital every 4 to 10 days with life threatening clusters of seizures which could only be stopped with life threatening IV steroids. The life he had lacked joy and fun, his life lacked the ability to attend school or create social relationships, our lives lacked all this too and added to this was the fear of being woken up by Alfie screaming into a seizure. We were at breaking point. His brain was so upset, and because of the drugs and seizures he was violent and aggressive. I feared for all our futures.

I did lots of research to find a way to save him and us from this treacherous life and medical cannabis kept appearing on the internet, Facebook groups and epilepsy support groups in America. We had a choice to accept what his doctors were saying, which was that they couldn't do anything and that he could likely die or become psychotic, or we could fight.

As you know we fought and we won and now Alfie is doing so well, going to school, making friends, even attending a birthday party only last week, something I would usually dread. This time I could go there feeling more confident, and he loved every minute, and even came home when I asked him!

You are now facing this fight. You shouldn't have to, you shouldn't be made to go through any more than you have. And whilst I welcome the swift moves the Government have made in providing the application and panel process, it still feels like parents of very sick children and patients with horrendous illness have a big fight on their hands which can never be right.

I am now working with End Our Pain to help give you the chance to get a prescription from your doctor for Medical cannabis oil like you can for any other prescription, without the bureaucracy and fear which currently surrounds this subject.

In the meantime, you must fight. Fight for your yourself and your child and family, inform yourselves, read evidence, look at products, know your subject. And if your doctor or specialist say no, don't accept it, stand up for you and your child's rights, don't be frightened to challenge them. Doctors are usually ill-informed on this subject and it is our job to educate them.

Go to your MP, go to the local press. Tell them what your life is like, don't hide it be honest. It is my understanding that this medication doesn't work for everyone but when it does it works wonders. You have the right to try this medication. Don't give up until you get that chance.

Hannah Deacon

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Frequently Asked Questions

*The definition of words or phrases in **bold** can be found in the glossary on page 7*

Who is eligible to apply to the panel for consideration?

- The panel is open to any patient who believes they would benefit from accessing **cannabis-based** medication. The **Home Office** has made clear that to qualify there must be 'exceptional clinical circumstances'.

Is the panel application the same for patients in Wales / Scotland / Northern Ireland

- Yes. But the steps following a successful application to the panel are slightly different because health is a devolved matter, but drugs policy is reserved to Westminster. Because **cannabis** is a **Schedule 1** drug under the Misuse of Drugs Act (1971), so it is reserved to Westminster, through the **Home Office**. Therefore, all applications go through the Home Office in London.

Do you have pay just to apply to the panel?

- There is no fee to apply to the panel and the Home Secretary has announced that all fees associated with applying for and/or receiving a licence are now waived.

Can I apply to the panel for a licence to grow my own cannabis for medical purposes?

- No. The panel has been established to consider licence applications for the use of **cannabis-based** medical products, not applications to grow your own.

Can I apply to the panel for a licence to use cannabis for recreational use?

- No. The Government has made it very clear that they are not considering legalising recreational use of cannabis. This panel, and the associated reviews announced by the Government, is solely for medical purposes.

Do you have to have travelled abroad and been treated with cannabis-based products to apply?

- At present the panel will only consider applications where the patient can provide evidence that the **cannabis-based** medicine has worked for their condition. This therefore gives an advantage to patients who are, or have been, in a financial and physical position to travel abroad and seek treatment. However, we have received reports that it was not the intention of the Government to insist that patients had travelled abroad to get evidence that medical cannabis works for them. Other forms of evidence will be given consideration. We are campaigning hard to get this guidance made clearer.

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What evidence do you need to present to a clinician that cannabis-based medication would help your condition?

- We would suggest drawing to the attention of your medical team about evidence that might support your application. This could include:
 - Evidence from clinical trials globally
 - **Anecdotal evidence**
 - Evidence found on the internet
 - This could be from medical trials in other jurisdictions
 - Or by referring to case studies – for example Alfie Dingley or Sophia Gibson
- We have added a resource bank to this Q+A with our recommended research papers. The **All Party Parliamentary Group (APPG)** report sets out the evidence base for various medical conditions.

What is the difference between CBD and THC?

- **CBD** and **THC** are the two most abundant of the many **cannabinoids** found in **cannabis**. They both interact with the body through the endocannabinoid system, a vital signalling system within the body which makes them responsible for regulating a wide array of functions.
- The biggest difference between the two is that **THC** binds with the receptors primarily found in the brain and the central nervous system (**cannabinoid 1** receptors). **CBD** does not bind with **cannabinoid** receptor 1, therefore there is no psychoactive effect.

Do you have to have tried every single alternative medicine for your condition before you can apply?

- Currently the application form appears to insist that you have tried every other medicine unsuccessfully. Therefore, indicating that **cannabis-based** medicines should be a medicine of last resort. We are campaigning to have this assumption of 'last resort' changed. This criteria should not put you off applying to the panel.

Have clinicians been given advice or recommendations on whether to apply to the panel?

- It is our understanding that currently no official guidance has been given to doctors about the benefits of medicine containing **THC**. Therefore, it is essential that if you believe you or someone you care for would benefit from access to medical cannabis, you read up about the evidence and, if necessary, constructively challenge your medical team.

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What happens if your clinician says no?

- Keep fighting. We would suggest having further conversations with your medical team and providing them with as much evidence as possible that medical **cannabis** would help you or your loved one. Alongside this, we would recommend that you contact your local MP and ask for their support and make them aware of your struggle. This way they can support you in conversations with your clinician or trust. And please feel free to let us know how you are getting on.
- Many clinicians have not been educated yet about the merits of **cannabis-based** medication so they are unwilling to prescribe. But we are working on changing this.

How long does it take to apply to the panel?

- No official timeframe has been given by the **Home Office** on how long each application will take as it will vary on a case-by-case process. The estimate provided by the Government is that the process should take 2-4 weeks.

What happens to the application once it has been submitted?

- Once the application has been submitted through the formal procedure, the expert panel's secretariat will triage the application to ensure the basic criteria has been met. Based on the information provided they may either request more information to support an application or refer the application to the expert panel for consideration.

If the panel make a positive decision about the application, then what happens?

- Once the panel have reached a decision they will share the finding with the Home Office or Department for Health in Northern Ireland, as appropriate. The applying clinician will then be invited to register their licence application. After this registration has been made they will request further information from the patient to show compliance with the UK Government's regulatory framework on the misuse of drugs.

If the application is successful, then who pays for the licence?

- All fees associated with the process have been waived.

If a domestic licence is granted, then how is the medicine accessed?

- If a domestic licence has been issued, then you will follow the usual process followed to import a controlled drug in the UK.

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Glossary

Advisory Committee on the Misuse of Drugs (ACMD)

- An advisory non-departmental public body which was established under the Misuse of Drugs Act in 1971. It functions to review and assess drugs in the UK and recommend the classification of new or existing drugs which might be being misused. It has at least 20 members who have done significant research and knowledge of the subject area.

Anecdotal evidence

- Evidence based on reports or observations of their personal experience or experience they have seen or heard about.

All Party Parliamentary Group (APPG)

- An All-Party Parliamentary group (APPG) is a grouping in the UK Parliament that is composed of politicians from all political parties. End Our Pain provides the secretarial services for the APPG on Medical Cannabis under Prescription.
- This group is chaired by Rt. Hon Sir Mike Penning MP and Co-Chaired by Tonia Antoniazzi MP.
- The sole purpose of this APPG is to help secure the legalisation of access to medical cannabis in the UK under prescription from a medical professional, including cannabis oil in formulations produced to a consistent, high quality, pharmaceutical grade and manufactured to GMP standard.

Cannabinoids

- Chemical compounds that can be manufactured or naturally derived from the **cannabis** plant. They act on cannabinoid receptors CB1 which are primary found in the brain and CB2 which are found in the immune system that alter neurotransmitter release in the brain, spinal chord and peripheral nerves. There are at least 113 different cannabinoids each with different effects.

Cannabis

- Is a broad term used to describe organic products derived from the **Cannabis** genus of plants (Source: **Cannabis** Scheduling Review Part 1 The therapeutic and medicinal benefits of **cannabis** based products – a review of recent evidence by Professor Dame Sally Davies).
- The **cannabis** plant has a number of different varieties (**Cannabis** Indica and **Cannabis** Sativa being the two main varieties of the **cannabis** plant used as medicine) and within those varieties there are many different strains. The **cannabis** plant is made up of different of chemical compounds (see below). **Cannabis** plants can be bred to vary the ratio between those compounds to produce different effects. Most street based **cannabis** has a very high quantity of THC and low quantity of **CBD** (see below).

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CBD

- Also known by its longer name of **cannabidiol**, it is a naturally occurring cannabinoid. It is legal in the UK as a food supplement but not as a medicine, so it can be bought on the high-street and internet but isn't regulated nor prescribed by a doctor. It is believed that high levels of **CBD** can reduce the psychoactive element of THC.

Drug Schedules

- Controlled drugs are assigned both a class and a schedule. These are laid out in the Misuse of Drugs Regulations.
- The class designates the drug's potential for harm and the penalties of possession and distribution.
- The schedule relates to the medical benefit of potentially addictive and harmful drugs. There are five different schedules, Schedule 1 being the most restrictive with regards to prescribing and storage.

Entourage Effect

- It is believed that where present together the chemical compounds in **cannabis** interact with one another to produce synergetic effects that they wouldn't do in isolation. (Source: Leafly)

Epidiolex

- A drug produced by GW Pharma that has currently been approved by the Food and Drug Administration (FDA) in the United States and is currently going through clinical trials in the UK to treat Lennox Gastaut syndrome and Dravet syndrome, both of which are rare forms of epilepsy. It is purified **CBD**.
- **Home Office**
- The Home Office (HO) is a ministerial department Government of the United Kingdom, responsible for immigration, security and law and order. It is also in charge of government policy on security-related issues such as drugs, counter-terrorism and ID cards.

Misuse of Drugs Act (1971)

- An Act of Parliament of the United Kingdom. It established the Home Secretary as the key player in the drug licensing system. The Act allowed the Government to authorise possession, supply, production and import or export of drugs to meet medical or scientific needs.

National Institute for Health and Care Excellence (NICE)

- Is an executive non-departmental public body of the Department of Health. It publishes guidelines on the appropriate treatment and care based on efficacy and cost effectiveness of drugs and treatments.

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Schedule 1

- Drugs in Schedule 1 are found to have little to no therapeutic value and are under the most restrictive controls. They cannot be lawfully possessed or prescribed. They may be used for research purposes, but a Home Office license is required.

Schedule 2

- Drugs in Schedule 2 are found to have some therapeutic value can be prescribed and legally possessed and supplied by pharmacists, doctors and possessed lawfully by anyone who has a prescription for them.

Terpenes

- A class of organic compounds produced by plants that give them their scent. They are found in plants and flowers. Over 100 have been identified in the **cannabis** plant. They can interact with other chemical compounds found in **cannabis** and the presence of different levels of terpenes can have different effects. It is believed that they improve the relationship between different cannabinoids and they have their own medicinal products (Source: Leafly)

THC

- Also known by its longer name of **tetrahydrocannabinol**. It is a cannabinoid that is the psychoactive element found in **cannabis** that can get users 'high'. It is currently a Schedule 1 and class B drug.

Whole plant cannabis

- It is believed that because of the presence of other cannabinoids and terpenes and the synergy of the entourage effect that using the whole of the **cannabis** plant, instead of isolating one or a limited number of compounds found within it is more effective as a medicine. (Source: Leafly)

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Resource Bank

- We would suggest looking at Dame Sally Davies review of evidence as well as the references You can see that report here and the references are listed below:
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/722010/CMO_Report Cannabis Products Web Accessible.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/722010/CMO_Report_Cannabis_Products_Web_Accessible.pdf)
- National Academies of Sciences, Engineering and Medicine, *The Current State of Evidence and Recommendations for Research Committee on the Health Effects of Marijuana: An Evidence Review and Research Agenda*, 2017. Available at <https://www.nap.edu/read/24625/chapter/1#xii>
- Health Products Regulatory Authority, **Cannabis for Medical Use - A Scientific Review**, 2017. Available at <https://www.hpra.ie/docs/default-source/publicationsforms/newsletters/cannabis-for-medical-use---a-scientific-review.pdf?sfvrsn=7>
- World Health Organization Expert Committee on Drug Dependence, *Cannabidiol (CBD) Critical Review Report*, 2018. Available at <http://www.who.int/medicines/access/controlledsubstances/WHOCBDReportMay2018-2.pdf?ua=1>
- World Health Organization Expert Committee on Drug Dependence, *Cannabidiol (CBD) Expert Peer Review 1*, 2018. Available at <http://www.who.int/medicines/access/controlledsubstances/Cannabidiolpeerreview1.pdf?ua=1>
- World Health Organization Expert Committee on Drug Dependence, *Cannabidiol (CBD) Expert Peer Review 2*, 2018. Available at <http://www.who.int/medicines/access/controlledsubstances/CannabidiolPeerreview2.pdf?ua=1>
- World Health Organization Expert Committee on Drug Dependence, *Pre-review: Cannabis plant and resin*, 2018. Available at http://www.who.int/medicines/access/controlledsubstances/ecdd_40_meeting/en
- World Health Organization Expert Committee on Drug Dependence, *Pre-review: Extracts and tinctures of cannabis*, 2018. Available at http://www.who.int/medicines/access/controlledsubstances/ecdd_40_meeting/en/
- Australian Government Department of Health Therapeutic Goods Administration, *Medicinal cannabis - guidance documents*, 2018. Available from <https://www.tga.gov.au/medicinal-cannabis-guidance-documents>

Also of use is the All-Party Parliamentary Group on Drug Reform's report on medical **cannabis** written by Professor Mike Barnes – it can be downloaded off the End Our Pain website here: <https://endourpain.org/appgreports/>