

Cannabis and epilepsy

Introduction

Cannabis for medicinal use is never far away from the news, however, reporting in the media has not always been accurate, often creating more confusion and misunderstanding around medical cannabis.

This factsheet intends to clarify the current law around cannabis, clear up misunderstanding and confusion and to explain what it specifically means for people with epilepsy.

Cannabis terminology explained

When people talk about cannabis, the following terminologies often pop up:

Cannabis oil

This is the oil extracted from the whole plant. It contains the psychoactive component THC (tetrahydrocannabinol), which is what makes a person feel high. Any cannabis oil which contains more than 0.2% of THC is illegal in the UK, unless prescribed by the NHS or a private prescriber approved by Healthcare Improvement Scotland.

Cannabis oil is not the same as CBD oil, which can be legally bought in shops and online, see below.

CBD (cannabidiol) oil

CBD oil contains less than 0.2% of THC. Because of its low THC content, it is legal to buy and consume in the UK. You can buy CBD oil (also sometimes referred to as hemp oil) in health food shops and online.

Quality and strength of CBD oils vary widely. Not all CBD oils are the same, some of them may be contaminated with pesticides, heavy metals and other harmful chemicals.

Cannabinoids

The cannabis plant is made up of many components, these are called cannabinoids. The two most well-known cannabinoids are CBD (cannabidiol) and THC (tetrahydrocannabinol).

Cannabis-based medicines

These are medications which have undergone clinical trials and have been licenced for use within the NHS. These could be medications based on CBD only or based on both CBD and THC.

Recreational cannabis

Cannabis bought on the street is illegal. It can vary in strength and quality and is entirely unregulated. Marijuana is the most common form of street cannabis.

Legal position of cannabis

On 1 November 2018, cannabis for medicinal use was made legal in the UK. This means that it can now be prescribed to treat conditions such as epilepsy. This law change also applies to the prescribing of cannabis which contains the psychoactive component tetrahydrocannabinol (THC).

Please note the change in legislation does not apply to the recreational use of cannabis. Possession and consumption of cannabis for recreational use remains illegal.

Clinical guidelines for prescribing cannabis

Although it is now legal to prescribe cannabis, the NHS has issued clinical guidelines which prescribing specialist doctors are expected to follow. These guidelines in effect narrow down the circumstances under which cannabis based medicines can be prescribed.

Cannabis based medicines can only be prescribed by a specialist doctor (not a GP). This specialist doctor needs to be on the General Medical Council's Specialist Register.

Cannabis based medicines should only be prescribed if there is an exceptional clinical need. Normally this means that you, or someone you care for, needs to have exhausted all available current treatment options first.

For epilepsy, this usually means drug treatment, surgery or the Ketogenic diet, if appropriate.

There is an exception to this strict prescribing process for the UK/Scotland's first licensed cannabis based medicine, ie **Epidyolex® (cannabidiol)**, please see below.

What can medical cannabis be prescribed for?

Clinical guidelines only currently recommend prescribing cannabis based medicines for three health conditions:

- two severe epilepsy syndromes, and soon seizures associated with Tuberous Sclerosis Complex subject to approval by the SMC (see below)
- severe nausea caused by chemotherapy treatment
- MS-related muscle spasticity

What does this mean for people with epilepsy in Scotland?

The role of the Scottish Medicines Consortium (SMC)

When a new drug comes on the market the Medicines and Healthcare Products Regulatory Agency (MHRA) of the UK Government first decide if a drug is legal for use in the UK. Once this is done, the Scottish Medicines Consortium (SMC) will review all the clinical evidence and trial data to decide if this drug can be prescribed in NHS Scotland. They will also look at the cost of the drug and may not approve it if it is too expensive.

Epidyolex® (cannabidiol)

As of September 2020, the SMC have approved Epidyolex (cannabidiol) as a treatment option for anyone aged two years and over who has Dravet or Lennox-Gastaut Syndrome. It is an adjunctive therapy, which means Epidyolex cannot be prescribed on its own but must be prescribed together with another medicine called clobazam.

Dravet and Lennox-Gastaut Syndrome are two rare forms of severe epilepsy and are associated with frequent, treatment-resistant seizures. Children and adults affected by these two syndromes often also have learning disability, autism, mobility problems and developmental delays.

The SMC are also currently considering an application to approve Epidyolex for use in NHS Scotland to treat seizures associated with Tuberous Sclerosis Complex (TSC) following the issuing of a licence by the UK body MHRA. These types of seizures are usually complex and are often resistant to treatment with anti-epileptic drugs.

Doctors will usually only prescribe Epidyolex for the above mentioned conditions in line with clinical guidelines, unless there are exceptional circumstances.

Unlicensed cannabis products

All medicines need to undergo strict clinical trials to test them for efficacy and safety before they can be licensed and prescribed for use in the NHS.

Clinical guidelines do not recommend the prescribing of untested and unlicensed cannabis based medicines, as their safety and effectiveness cannot be proven.

Clinical guidelines also do not support the prescribing of artisanal cannabis products. These are the kind of products which can be legally bought in health food shops and online containing mainly CBD. Some cannabis products ordered from abroad may contain more than the permissible amount of the psychoactive component THC, which makes it illegal to buy without a prescription.

A prescribing doctor may be reluctant to go against clinical guidelines as they are legally liable for the prescribing and the consequent effects of a drug. They must also be satisfied that there is enough evidence or experience of using the medicine and take full responsibility for overseeing the person's care, and any monitoring.

Cannabis based licensed medicines

There are currently three cannabis based medicines which are licensed for NHS use.

- **Epidyolex**, for certain types of epilepsy mentioned above.
- **Nabilone** for chemotherapy patients
- **Nabiximols (Sativex)** for MS patients

Is cannabis safe?

One of the main reasons why clinical guidelines do not recommend the prescribing of unlicensed cannabis based medications or artisanal cannabis products is because there are concerns about possible side effects and long term effects on a child's/young person's developing brain.

Clinical trials on CBD based medicines have also shown the potential of liver toxicity as a side effect.

Taking non-prescribed cannabis/CBD based products

Many people have expressed disappointment at the apparent restrictiveness of the prescribing of medical cannabis following the change in legislation, which may prevent them from accessing medical cannabis via the NHS for themselves or those they care for.

Some campaigners and families also argue that preparations containing THC are more effective in controlling seizures. There have been a number of cases of families moving temporarily abroad to gain access to cannabis oil containing THC for their child, often at considerable expense. Some of them have reported significant improvements in their child's quality of life and seizure reduction and want to continue accessing cannabis oil containing THC in the UK.

However, there are currently no completed large-scale, high quality medical trials to show this is effective and safe in children with epilepsy.

It is not our place to tell individuals and families what they should or should not do. If you decide to buy cannabis based products (the legally available version, ie CBD oil, or the illegal version containing THC) we would always urge anyone to let their or their child's healthcare professional know. The main reason for this is that cannabis based products can sometimes interfere with anti-epileptic medication and can make seizures or side effects worse.

Your specialist will, however, not be able to give medical advice on strength and dosage of unlicensed products.

Never stop your or your child's anti-epileptic drugs without medical advice and supervision, as this could trigger major seizures and put your or your child's life in danger.

Never substitute your or your child's anti-epileptic medication with non-prescribed cannabis products unless advised by a specialist.

Unlicensed cannabis products also vary in strength and quality. Some products sold legally may actually contain more than the permissible amount of the psychoactive component THC, or they may be contaminated with pesticides and other harmful chemicals.

Contact us

If you want to talk to us about anything in this factsheet, please contact us on our helpline 0808 800 2200, email us at contact@epilepsyscotland.org.uk, or contact us via social media. We will not judge you and will treat your query in strict confidence.

Our resources are always free. If you would like to support our work please text FACTS to 70085 to donate £3. Texts cost £3 plus one standard rate message.



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