

FAQ

April 2021

Medical Cannabis

Guide for Parents & Carers

ADVOCACY | EDUCATION | SUPPORT

MEDCAN

Parents | Carers | Patients

Medcan Support is an independent, not-for-profit hub for education and support around cannabis and childhood epilepsy. We are supported by clinicians and researchers in the field of cannabis and produce information for parents in the UK about this treatment. Through our work, we are contacted by many parents and carers who have questions about how to access this treatment. Members of our expert committee have responded to a list of frequently asked questions.

www.medcansupport.co.uk

Our Team



— CO-FOUNDER & CHAIR

Matt Hughes



— CO-FOUNDER & VICE CHAIR

Hannah Deacon



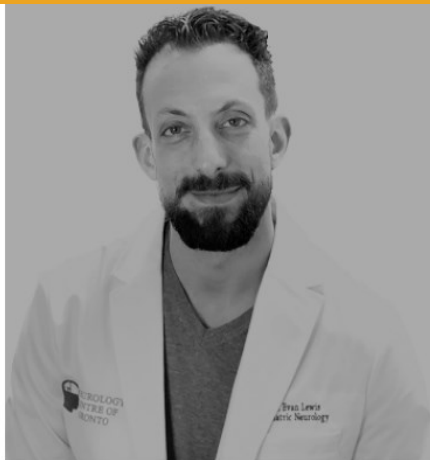
— CANNABIS RESEARCH AND SCIENTIFIC LEAD

Dr Callie Seaman



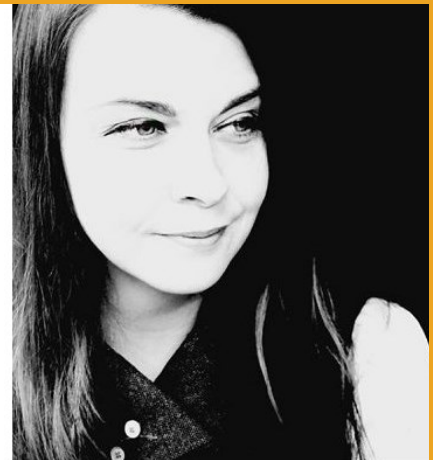
— PEDIATRIC CANNABIS CONSULTANT

**Dr Bonni Goldstein
MD**



— PEDIATRIC NEUROLOGIST AND CLINICAL NEUROPHYSIOLOGIST

Dr Evan Lewis



— CBD INDUSTRY EXPERT

Jade Proudman

Access & Prescriptions

Information about how to access medical cannabis treatment, who can prescribe.

1. How do I get a prescription for medical cannabis?

At the time of writing, the NHS is not prescribing medical cannabis, so patients must be prepared to pay for a private prescription. However, an NHS specialist is legally permitted to prescribe the medicine, so it's always worth asking! See question 2 for more on this. There are only two clinics prescribing for paediatrics, The Medical Cannabis Clinics or Sapphire, details are on our website. Fill in the details required – this usually includes information about your child and medical history. When the clinic responds, they will provide next steps which will vary by provider. They may contact your neurologist on your behalf. Your records will be sent to the clinic's consultant who will decide whether you are eligible for medical cannabis treatments. Clinics will not see you without the relevant medical records. If you are eligible for medical cannabis treatment, you will be sent an appointment.

2. Can I get an NHS prescription for medical cannabis?

Currently medical cannabis is only available in the private sector. Limited guidance for doctors means that no new NHS prescriptions for medical cannabis have been issued in last 2 years. Legally there is no barrier, but in practical terms this is almost impossible. There are three exceptions. Sativex is a cannabis medicine licensed for use with spasticity in multiple sclerosis and can be prescribed on the NHS. Also, Epidyolex can now be prescribed on the NHS for certain childhood epilepsies (Dravet and Lennox-Gastaut syndromes) alongside another drug called Clobazam. Finally, a synthetic cannabis called Nabilone is also prescribable on the NHS for severe nausea and vomiting, usually during chemotherapy.

3. Who can prescribe medical cannabis in the UK?

Any doctor on GMC Specialist Register can prescribe. This is usually a hospital consultant. A GP can prescribe under shared care arrangements under the direction of a specialist. You are more likely to be prescribed medical cannabis from a doctor working for a medical cannabis clinic as those doctors are more likely to have been trained in cannabis medicine.

4. Do I need a referral from my doctor?

In most cannabis clinics you can self-refer but they will need to contact your doctor to confirm your child's medical history.

5. My NHS neurologist/consultant isn't supportive—what can I do?

A medical cannabis clinic can still see you, and this shouldn't be a barrier to treatment. We suggest you keep your NHS clinician informed and up to date with progress.

Understanding Medical Cannabis

Information about how medical cannabis works on the body and the differences between CBD, THC and recreational and medical cannabis

1. What is the Endocannabinoid System?

This is the body's own "cannabis" system. We all have cannabinoid nerve receptors in our brain and elsewhere in the body. We produce chemicals, called endocannabinoids, which lock on to those receptors and perform vital functions. This system is responsible for such things as pain control, mood control, antiinflammation response, control of bodily movement, epilepsy, etc. The plant cannabinoids, called phytocannabinoids, help that system by also locking on to those receptors. This is why cannabis has so many potential uses.

2. What are phytocannabinoids?

Phytocannabinoids are cannabinoids produced within plants, 147 of which we currently know. CBD and THC are the most studied and talked about but many other minor phytocannabinoids make up the compounds found in the cannabis plant. Plants that produce phytocannabinoids include Kava, Rosemary, Liverwort, Electric Daisy, Echinacea, Cacao, Helichrysum, Pepper Trees, Black Truffles, and of course, Cannabis. The world of cannabinoids can generally be broken down into two main categories: phytocannabinoids and endocannabinoids. The difference between the two is straightforward. Phytocannabinoids are produced by plants, while endocannabinoids are produced by mammals.

3. What is the difference between CBD and THC?

Both THC and CBD have medical properties. THC is the cannabinoid that is the major part of recreational cannabis and in high doses can cause impairment. In lower doses it is a muscle relaxant, can help with sleep and many different causes of pain. It can also help with nausea and other chemotherapy related side effects and shown to be effective in epilepsy. CBD does not cause impairment. CBD is often used in anxiety, epilepsy and pain management also. There is much overlap between the two when controlling symptoms. When you are assessed by a doctor they will determine the combination that is most likely to help your symptoms. Most doctors start with a higher CBD product with small amounts of THC and increase the dose slowly, but it will depend on your previous exposure to cannabis and your symptoms. If prescribed carefully, the side effects one commonly recognises with recreational cannabis and unopposed THC use are usually very minimal and well tolerated.

4. What is the entourage effect?

Cannabis not only contains phytocannabinoids, but also other chemicals called terpenes (which give smell) and flavonoids (which give colour). There are over 100 terpenes and flavonoids. It is thought that the full plant with all those components in various proportions give a better medical effect than the individual parts. That is the entourage effect. Science doesn't fully understand the interaction of phytocannabinoids and terpenes within the human body, but observational data and open label studies are leaning towards use of the whole plant has a better medical effect than isolated parts.

5. What is the difference between recreational and medical cannabis?

Generally, recreational cannabis is high in THC and low in CBD – opposite to most of the initial medical cannabis prescriptions. Also, recreational cannabis comes with no guarantees of safety and quality and may well be contaminated with other chemicals like heavy metals and pesticides. Usually, you will not know what's in recreational cannabis and one batch is likely to be different from the next.

6. Can the CBD I get over-the-counter work just as well?

Over-the-counter CBD is usually derived from hemp. Hemp is a cannabis strain that has been grown for centuries for its strong stem that is used for paper and building materials, for example. It is also used for hemp seed oil production, which is a very healthy oil which can be used in cooking. However, hemp contains high levels of CBD and very little other cannabinoids and few of the other components, like terpenes and flavonoids. It is thought by many that these other components are essential for the full medical benefit of the plant (the entourage effect). So, over-the-counter CBD might be useful for some conditions but less likely to help than the prescribed medicine. Also note the over-the-counter CBD products cannot make any medical claims for their products and they are not subject to such stringent controls as a medical product. It is sometimes difficult to know what to take and in what dose. Look at some websites to see good quality products such as savagecabbageltd.com

Medical Cannabis UK law

Understanding what's legal under UK law.

1. Can I grow my own cannabis for myself or my loved one?

You are not legally allowed to do this. We don't encourage anyone to break the law. Medcan Support believe that regulated, GMP quality cannabis provided under expert care and with monitored dosage is the right way to access medical cannabis. GMP (Good Manufacturing Practice) means that the products are high quality, consistent and free from any contaminants.

2. What if I get arrested / stopped by police?

It's very unlikely to happen, especially give the fact that cannabis oil is used for treating children and is very discreet and if administration is in public, tends to go unnoticed. Although cannabis oil does smell of cannabis, it's not a strong odour.

If in the even you are stopped or questioned, you prescription is enough to show its legally prescribed.

Medical Cannabis & Epilepsy

Common questions around cannabis &
epilepsy

1. How is medical cannabis taken or administered?

Medical cannabis for childhood epilepsy is usually prescribed as an oil. For the best bioavailability it's recommended to leave under the tongue, but generally with children suffering develop delay or learning difficulties, this is simply unrealistic. Swallowing is fine and may require a little bit more oil to reach therapeutic dose.

For children who may have difficulties swallowing, the oil can be administered via feeding tubes although not recommended to mix with water.

2. What dose should I take?

Your doctor will advise on the dose. Generally, you will be started on a low dose – at around 1mg per kg of body weight and gradually increase in increments. Studies show that around 10–15mgs/kg is in the therapeutic range, but each child will respond differently. Some may require much less and others much more. If the doctor wants to add in THC then again it starts low (even as low as 1mg THC) and builds up slowly.

3. How long does the cannabis effect last?

Taking oil will take approx. 1 hour to take effect and lasts for approx. 6 hours. Generally the daily dose is split into smaller doses 2–3 a day.

4. When should I start seeing cannabis reduce seizures?

This is very much down to how the individual child responds. Generally parents see an improvement in alertness and awareness of surroundings/environment, before seizures are seen to reduce. It can take 6–8 weeks, sometimes longer before full therapeutic effect is seen. It's not uncommon to see very little effect to seizures, but this could be the profile of the oil (makeup of phytocannabinoids and terpenes) is not right for your child and better effect would be seen using a different product.

5. I'm using Epidyolex and want to use full extract privately prescribed?

In the first instance speak with your NHS clinicians about your decision to move to a private doctor who will oversee the cannabis prescription. The private doctor will likely want to speak with your NHS clinician for them to arrange a weaning plan of Epidyolex and transition to private prescription.

6. We are on the ketogenic diet, can we use cannabis?

Yes you can use CBD/cannabis oil in conjunction with the Ketogenic Diet, but be very careful to the carrier used. Although most CBD oils use MCT oils as the carrier, some have added flavourings which could be from sugars which would impact ketones produced. If prescribed your clinician should be aware of the carrier oils of products. Speak with your ketogenic dietician if uncertain.

7. How do you change from one cannabis oil to another?

Your doctor will advise on this. Generally though as one oil is weaned, another is introduced.

8. Can CBD / Cannabis be administered in Hospital?

If your using an over the counter CBD oil then no you won't be allowed to administer it in Hospital, if however you have a prescribed oil, then you should be allowed to administer it. You may need to give the hospital notice and let them know the dosing regime.

9. Can CBD / Cannabis be administered in playgroup / School?

If it's a prescribed oil with the correct pharmacy labelling on the bottle, this should be fine, but it has been known that some schools are hesitant in administration and ask parents do so.

10. Our doctor/Epilepsy nurse says CBD (Epidyolex) can only be prescribed for LGS/Dravet—Can we still get a private prescription?

Yes, although NICE recommend Epidyolex for LGS/Dravet, this has no impact on whether you can be prescribed a broad/full extract oil privately. That decision is down to the prescribing doctor.

Safety & Side Effects

Medical cannabis is a very safe treatment option, but there are things you should be aware of.

1. Is Medical Cannabis suitable for everyone?

Like any medicine, not everyone is suitable for medical cannabis treatment. People with active schizophrenia, for example, may not be suitable as well as some people with heart rhythm problems. Medical cannabis doesn't mix very well with some other medicines that you may be taking. Your doctor will check whether it is suitable for you before prescribing.

2. What are the side effects of medical cannabis?

CBD is generally very safe, but can give some people stomach upsets, diarrhoea, dizziness and tiredness. THC has more side effects and these can include dizziness, disorientation, drowsiness and dry mouth. Your doctor will start you on a low dose and increase it gradually so that side effects are minimised. Serious side effects, like a psychotic episode, should be avoided by careful screening of whether you are suitable for treatment in the first place.

3. Can you overdose on Cannabis?

You can take more than prescribed, but fortunately no one has died directly from an overdose of cannabis – unlike some medicines like opioids. Overdosing can be unpleasant and can give, for example, palpitations, sweating, dizziness, disorientation and even, in very rare cases, psychotic reactions but these will pass after a few hours. A very large overdose can be serious and if you are concerned, go to A&E and tell them what you have taken.

4. Does THC effect the developing brain?

Some reports have said that THC can damage the developing brain in children and adolescents. There is no evidence of this in the low doses generally used in cannabis medicine. There are some reports of such problems in high THC recreational cannabis users, but those reports are also controversial. In the low THC doses used in medical practice, that risk is very small indeed.

5. Can I take cannabis while pregnant or breastfeeding?

No woman should really take any medicine whilst pregnant or breastfeeding. However, occasionally taking some medicine is essential for a medical condition. If your condition necessitates continuing on cannabis (such as epilepsy) then be reassured that there are no definite "syndromes" associated with cannabis. High THC recreational cannabis use may cause low birthweight, but the evidence for any other problems in the newborn child is not clear. Avoid if possible.

6. What should I look for in a product so I know it's safe?

Properly prescribed medical cannabis treatment by a specialist ensures that you will receive safe products. Prescribed medical cannabis treatment will be EU GMP standard and thus meets high quality standards of consistency. It comes with a certificate of analysis so you can be confident it contains exactly what is required.

2. Why is there MCT (medium chain triglyceride) oil in my product?

This is a carrier oil, which helps to enhance the availability of the cannabis after consumption. MCT oil is arguably the most effective option, however some brands will try other sources, such as olive oil. Be aware of the carrier oil as some people may be allergic to some oils, like peanut oil.

The Cost of Medical Cannabis

Medical cannabis is, at present, available only via private prescription. Medcan Support advocates for and is committed to fighting for this treatment to be available on the NHS. However, for now, there are various costs associated with private treatment.

1. What will I pay for a medical cannabis prescription ?

You will pay for the cost of treatments – an average of £500 per month for your products. Families of children with epilepsy will see costs from £1000+ per month but costs are coming down. You will also pay the cost of import, which can be around £150 per prescription. However, now bulk importation of medical cannabis products are permitted, we see prices reducing as this cost is split between multiple patients. You will also pay the costs of the pharmacy as well as the cost of any consultation – face to face or telehealth with your consultant. This is usually around £200 for the first consultation and less for follow-up visits, which need to be monthly at first but if you are stable then can then be less frequent.

2. Is it possible to get cheaper medical cannabis?

Prices are coming down and are currently around half the price they were during January 2020. Prices will continue to decline. If you have a qualifying condition, then access via Project Twenty21 may be an option for you. Treatment will available at be a capped cost but will restrict a doctor to prescribe only certain products. Currently paediatric epilepsy is not covered by Project Twenty21 but they are looking to change this as soon as possible. Check our website or facebook group for updates.

3. Will I have to fundraise to pay for treatments?

Some families, particularly those with children with severe epilepsy, fundraise for medical cannabis treatments as their costs can be very high. Sapphire Foundation also allow for parents to apply for funding to help cover the costs of prescriptions, further details can be found on <https://www.sapphirefoundation.co.uk/>

Intractable is another charity setup by families who struggled to pay for private prescriptions who can also help with funding. Adults can access medical cannabis on Project Twenty21 If you have a qualifying condition. Treatment will available at a capped cost but will restrict a doctor to prescribe only certain products. It is only available at the moment for those with pain and psychiatric conditions, like anxiety and epilepsy. There is information about Project Twenty21 on the Drug Science website.

CBD OILS & NOVEL FOODS

CBD extracts are being sold as a food and as food supplements in the UK. They are widely available in shops, cafés and for sale online. CBD is now regulated under Novel Foods by the Food Standard Agency (FSA).

1. What is novel foods ?

Novel foods are foods which have not been widely consumed by people in the UK or European Union (EU) before May 1997. This means that the foods don't have a 'history of consumption'. CBD is now classified as a Novel Food.

2. Will the CBD oil I've been using still be available?

The Food Standards Agency (FSA) is giving the CBD industry a deadline of 31 March 2021 to submit valid novel food authorisation applications. After 31 March 2021, only products which have submitted a valid application will be allowed to remain on the market. The authorisation process ensures novel foods meet legal standards, including on safety and content. Please check with your distributor of your oil or the manufacturer.

3. My child is well on CBD oil, but it won't be available after the 31st—what should I do?

In these circumstances we suggest families speak with one of the clinics (details on website) to see if an alternative CBD oil is available under clinical guidance.

4. What is white label CBD?

'White labelling' refers to the process of rebranding a product created by a manufacturer in order to sell it as your own. There are many oils using different brands, but the source of the oil is from the same manufacturer with identical ingredients.

5. What is a COA

Certificate Of Analysis (COA) is a test of the oil to check for phytocannabinoids, contamination, like heavy metals, bacteria and viruses. A good quality oil should come with this type of analysis which should be available on the manufacturers website. If you can find one, ask to view it before purchasing. More information about COA and what to look for and how to read one is available at <https://medcansupport.co.uk/labanalysis/>