

Cannabis and Parkinson's: the views of people with Parkinson's and health and care professionals

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Introduction

The UK government reclassified cannabis-derived medicinal products on 1 November 2018. This means that they are available on prescription for some conditions, but not Parkinson's.

To be classified as a cannabis-derived medicinal product, a product must:

- be produced for medicinal use in humans
- contain cannabis, cannabis resin, cannabidiol or a cannabidiol derivative
- be a medicinal product

If a product meets this definition and is licensed by the Medicines and Healthcare products Regulatory Agency, it will be available for prescription. There are various guidelines in place for professionals to prescribe licensed cannabis-derived products, although as far as we are aware none of these guidelines specifically address questions around use in Parkinson's.

In this report we will refer to people using cannabis-derived products, as there is not a medicinal product licensed for Parkinson's.

Studies have revealed little scientific evidence that cannabis-derived products can ease a person's Parkinson's symptoms. But we frequently hear anecdotal evidence from people with the condition that it helps to relieve their symptoms.

We want to better understand the views and experiences of our community, about whether cannabis-derived products help with their Parkinson's symptoms.

To do this, we ran two confidential surveys to gather the views of people with Parkinson's and health and care professionals around cannabis-derived products. This report summarises the results of those surveys.

We did not try to recruit specific groups of respondents – those that are currently using, have used, are interested in using or are not interested in using cannabis-derived products.

It was an open call for views, so we should recognise that the findings could be skewed towards one group. Based on anecdotal conversations we believe that the findings represent the general views of the Parkinson's population across the UK, however this cannot be validated.

Using these findings, we want to develop our own policy position on cannabis and Parkinson's. We also think the results will help us to decide our future activities.

This report outlines the findings of both surveys. The findings are organised by question theme.

Acknowledgements

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- Dr Camille Carroll, Consultant Neurologist and Dr Janine Barnes, Specialist Neurology Pharmacist, who shared their views on the survey design
- everyone who completed the survey, and staff and supporters who shared the survey with their networks
- Cathal Doyle, Sigita Stankeviciute and Rachel Joseph, who helped input the surveys and analyse the data

Executive summary

A total of 1,660 people with Parkinson's completed the cannabis and Parkinson's survey, which ran from 14 January to 24 March 2019. It was available both online (691 respondents) and as a paper version (909 respondents). It was distributed to all members with the winter edition of *The Parkinson* magazine.

29 health and care professionals completed a different survey. It was available online from 4 February to 24 March 2019 and was promoted through the UK Parkinson's Excellence Network newsletter and directly to professionals.

Key findings from survey respondents

- 59% of people with Parkinson's haven't used cannabis-derived products before but would consider using them to control their symptoms.
- 26% of people with Parkinson's have used cannabis-derived products (16% are currently using them for their Parkinson's and 10% have used them in the past).
- 16% of people with Parkinson's have not used cannabis-derived products and are not interested in using them in the future.
- Cannabidiol (CBD oil) is the most used cannabis-derived product. Those interested in using a cannabis-derived product in the future agree this is what they're most interested in using. Professionals also state this is the most widely used cannabis-derived product among their patients.
- People who currently use cannabis-derived products, and those who have previously used them, buy them from high street shops. Professionals confirmed this is where their patients report getting them. However, 87% of people who haven't used cannabis-derived products said they would want the cannabis-derived product to be prescribed by a doctor or pharmacist.
- All respondents agreed the primary reason to use cannabis-derived products is to ease their Parkinson's symptoms.
- People currently using, and those who have used cannabis-derived products in the past, said that they are most effective at easing anxiety. However, those that haven't used them think they would be most useful to ease stiffness. Professionals said that they seem to be most effective at easing stiffness, intense or vivid dreams, difficulties concentrating, slowness and constipation.
- Respondents who have used cannabis-derived products in the past said they didn't experience side effects, and that the products didn't interact with their Parkinson's medication. This was backed by professionals. However, people who haven't used them are worried about potential side effects and interactions with Parkinson's medication.
- Most people currently using cannabis-derived products, or those who have used them in the past, haven't sought advice from professionals before using them. Those who did seek advice are split on whether the advice was helpful.
- Professionals are regularly asked about using cannabis-derived products by their patients. 70% of professional respondents offer advice. 86% of respondents are not confident about prescribing a cannabis-based medicinal product for their patients, and many are not sure if the currently available prescribing guidance is fit for purpose (guidelines do not currently mention Parkinson's).
- Overwhelmingly, people with Parkinson's would continue to use, or start using, cannabis-derived products if there is robust evidence that they are safe and effective in treating Parkinson's symptoms. Professionals supported this view.

Based on these findings, Parkinson's UK should:

- produce our policy position on Parkinson's and cannabis
- call for more clinical studies into the impact of cannabis on Parkinson's symptoms
- produce information resources and guidance on the use of cannabis-derived products
- engage with the government to ensure they include Parkinson's in any future legislative changes, including issuing clearer treatment guidelines

Demographics of survey respondents and cannabis use

We asked survey respondents when they were diagnosed with Parkinson's. Answers ranged from 1954 to 2019. However, those diagnosed between 2014 and 2017 had the highest response rate to this survey.

We grouped respondents into age brackets of five years. The youngest respondent was aged between 25 and 29, and the oldest was in the 90+ age bracket. The three largest groups of respondents (at almost 61%) were aged between 65 and 79.

Using the English population projections of the number of people living with Parkinson's, the Parkinson's population is older. Those aged between 65 and 79 make up 50% of the Parkinson's population. Those aged between 80 and 84 make up 19% of the Parkinson's population, and those aged between 85 and 89 make up 12%.

81% of people with Parkinson's that responded to this survey live in England, 6% live in Northern Ireland, 7% live in Scotland and 6% live in Wales. These figures compare well with the proportion of people living with Parkinson's in each of the countries.

Cannabis use

2% of respondents said they currently use cannabis recreationally. 11% said they have used cannabis recreationally in the past. 87% of respondents said they have never used cannabis recreationally.

Those aged between 40 and 49 had the highest proportion of people sharing that they have used cannabis recreationally. Those aged between 80 and 90+ were least likely to have used cannabis recreationally.

59% of respondents said they haven't tried a cannabis-derived product but would consider using one. 16% said they are currently using a cannabis-derived product to control their Parkinson's symptoms. 16% said they haven't tried one and wouldn't be interested in doing so. And 9% of respondents said they have used a cannabis-derived product in the past to ease their Parkinson's symptoms.

Respondent groups between 70 and 79 are the most likely to be using a cannabis-derived product to control their Parkinson's symptoms. Those aged between 60 and 74 are the most likely to have used cannabis in the past for their Parkinson's symptoms. And respondents between 65 and 79 are the most uninterested group in using a cannabis-derived product.

Professionals

29 health and care professionals responded to the survey. 55% of the professionals who responded practise in Scotland, and the rest practise in England. We are unsure why the response rate was larger in Scotland than England the rest of the UK. It could be due to greater promotion of the survey to professionals, and a greater focus by the government and media on cannabis-derived products in helping to control symptoms for those living with long-term conditions.

Of the respondents to the professional survey:

- 69% were Parkinson's nurses
- 14% were geriatricians
- 10% were allied health professionals (physiotherapists, occupational therapists or speech or language therapists)
- 7% were neurologists

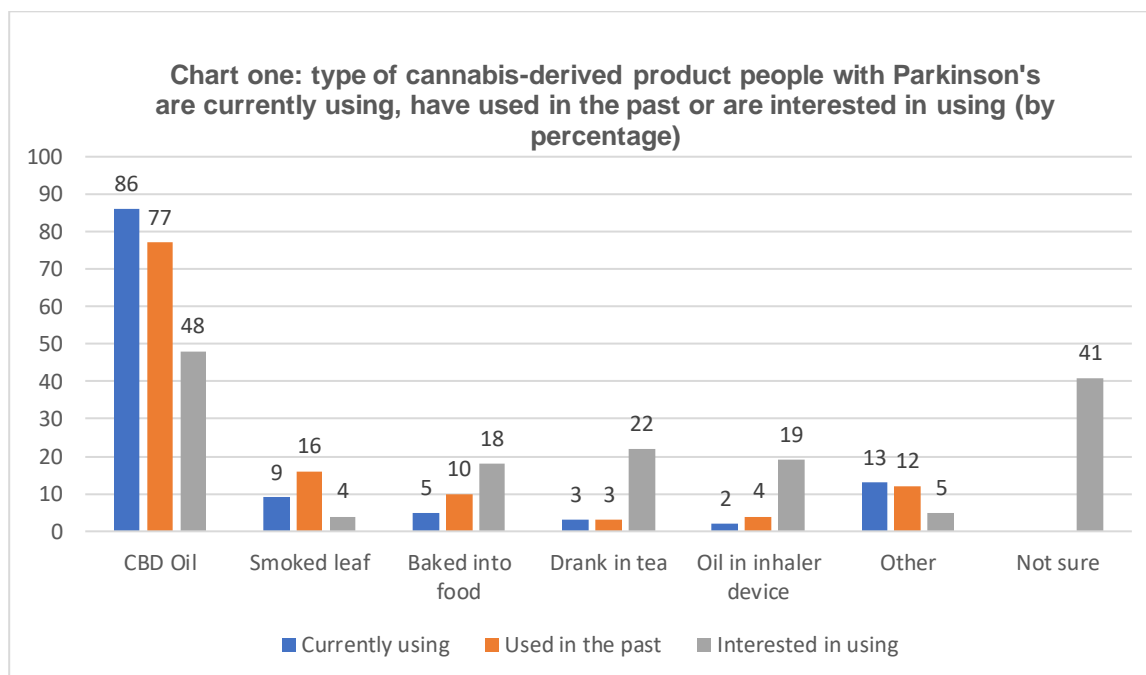
72% of the professionals who responded see between 100 and 500 people with Parkinson's each year. Some of these professionals also see patients with other conditions (such as arthritis, MS and stroke) who use cannabis-derived products to ease their symptoms.

Cannabis product used, source, cost and frequency of use

We asked people with Parkinson's which cannabis-derived products they currently use, have used in the past or are interested in using in the future.

CBD oil is the most popular cannabis-derived product according to the survey. 86% of those currently using a cannabis-derived product said they use CBD oil, compared to 77% who have used a cannabis-derived product in the past, and 48% of those who haven't used a cannabis-derived product, but are interested in using one in the future.

Chart one shows the other products the three groups of respondents are currently using, have used in the past or are interested in using in the future.



Some of the 'other' cannabis-derived products that respondents are currently using, or have used in the past, include hemp seed oil, capsules, cream or paste, jelly sweets, e-cigarettes, CBD capsules or tablets, vaporised flower, drops, chocolate and CBD/Tetrahydrocannabinol (THC) oil.

83% of professionals responding to the survey said that CBD oil is the most popular form of cannabis-derived products that their patients use, followed by smoked leaf at 28%, and patients baking it into their food at 17%.

Source and cost of cannabis-derived products

The greatest number of respondents who are currently using a cannabis-derived product (41%) or have used one in the past (43%) said they would buy it from a high street shop. Those who haven't used cannabis, but may be interested in doing so, stated overwhelmingly at 87% that they would want it to be prescribed by a doctor or pharmacist.

Table one shows where people with Parkinson's would feel happy getting their cannabis-derived product from.

Table one: source of cannabis-derived product by percentage

Product source	People who are currently using a cannabis-derived product	People who have used a cannabis-derived product in the past	People who are interested in using a cannabis-derived product
Prescribed by doctor or pharmacist	1%	0.65%	87%

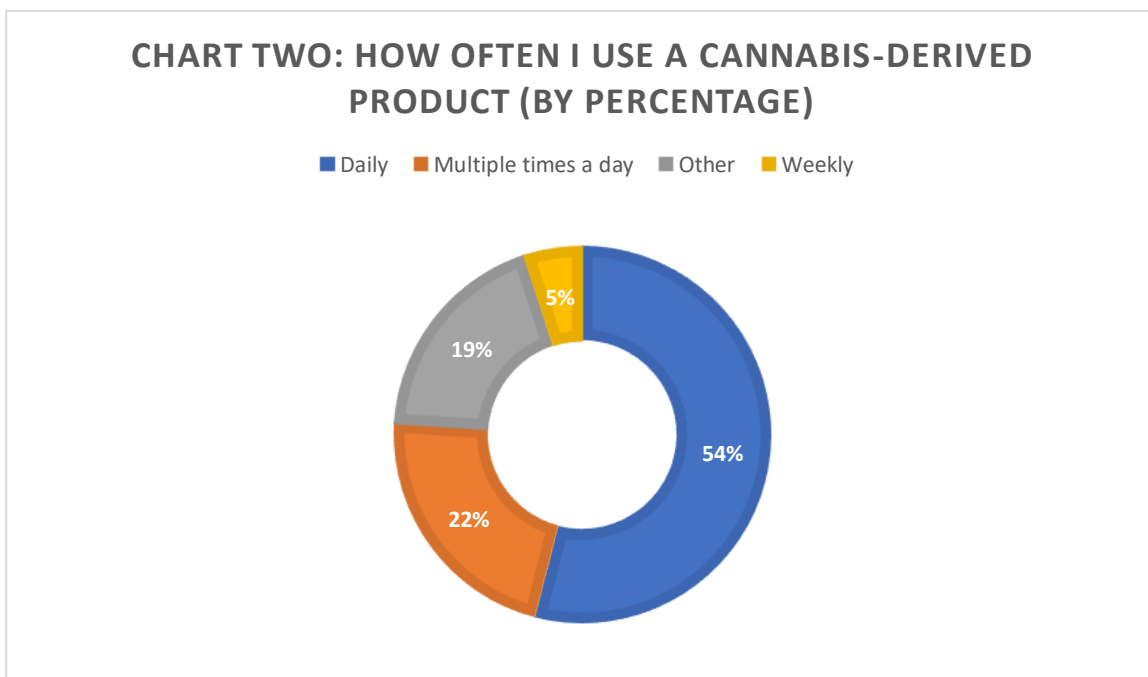
Bought from high street shop	41%	44%	39%
Friends/family	16%	21%	9%
Bought online	39%	29%	19%
Bought from a dealer	7%	8%	3%
Other	5%	8%	1%

Professionals said that the most common places their patients get their cannabis-derived products from are a high street shop, online, from friends or buying from a dealer.

Some respondents shared how much they spend on cannabis per month. This ranges from £0 to £230 per month. The average is £29.85 per month.

How often people with Parkinson’s use cannabis-derived products

Over three quarters of the people with Parkinson’s who currently use cannabis-derived products said they use them daily. Chart two shows the frequency of use.

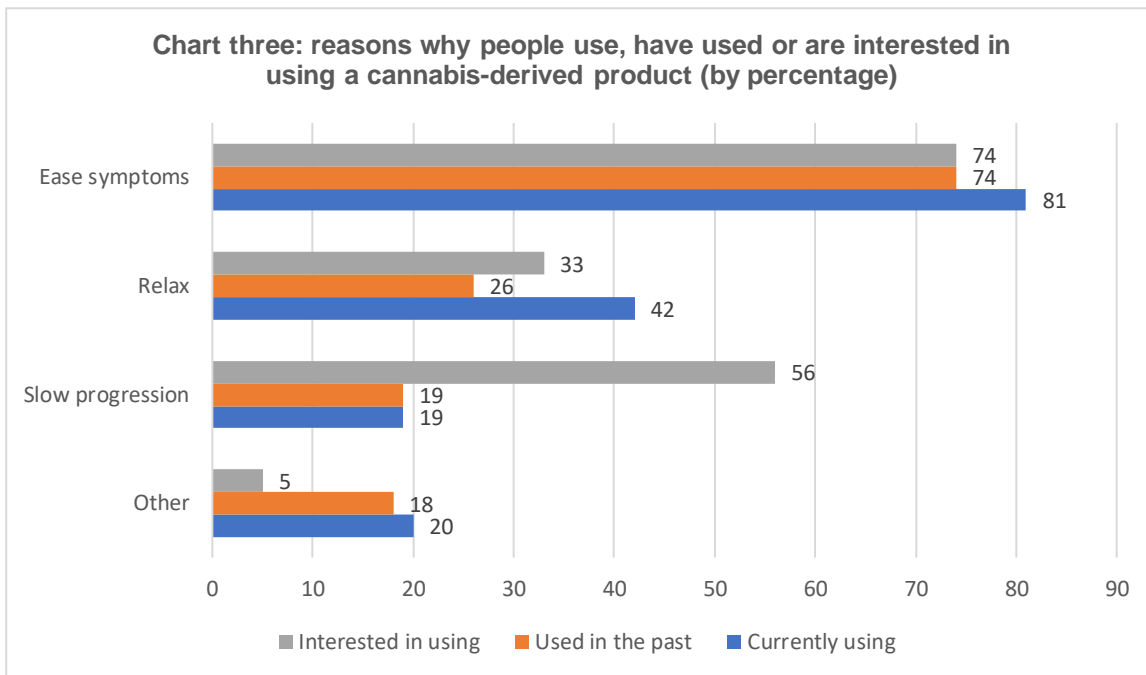


Of the respondents that said ‘other’, this ranged from twice a day and three to five times a week, to on an ad hoc basis and occasionally.

Why people use, have used and are interested in using cannabis

Overwhelmingly the greatest reason people with Parkinson’s are using, have used or are interested in using a cannabis-derived product is to ease their symptoms.

Chart three outlines this.



The ‘other’ responses included that cannabis-derived products help to ease a specific symptom such as restless legs, pain and anxiety, or to help with sleeping.

Some other respondents shared that they wanted to see if the cannabis-derived product had an effect, while others noted it was recommended by someone, or they used it as an experiment.

Cannabis effectiveness and side effects

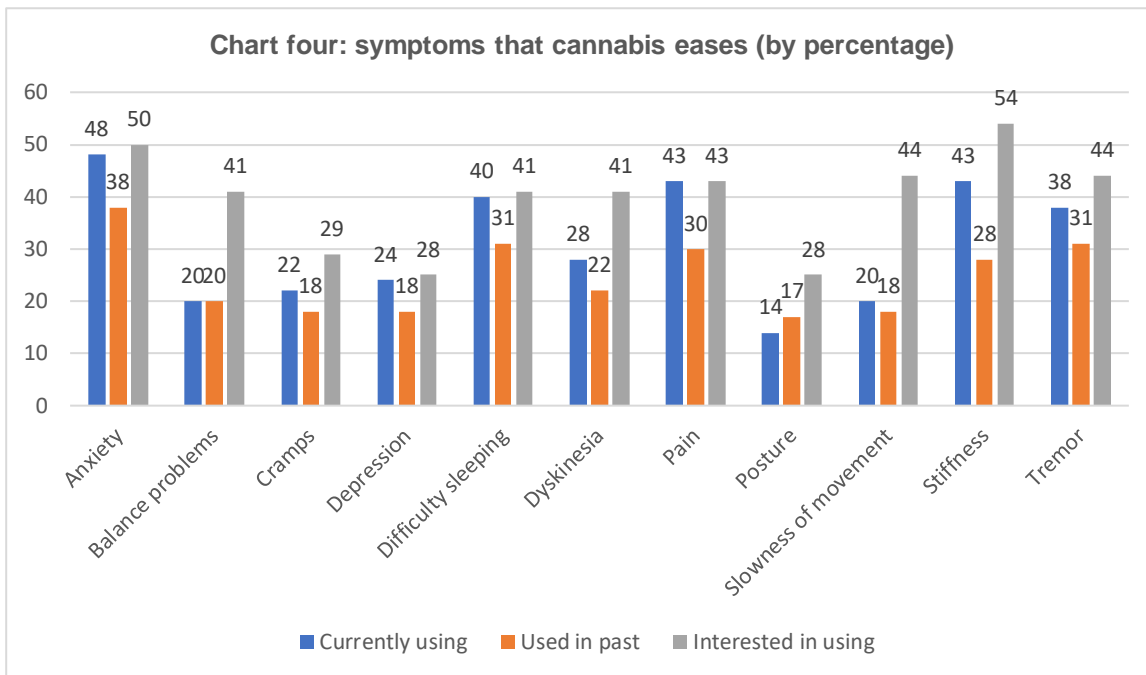
We asked people with Parkinson’s to share which symptoms cannabis-derived products ease or may ease if they haven’t used one before. We took the standardised symptoms used in the widely used non-motor symptoms questionnaire.¹

People who are currently using cannabis-derived products, and those who have used them in the past, agree in highest percentage that it eases their anxiety.

However, respondents who haven’t tried cannabis-derived products, but are interested in do so, think in highest percentage that it may ease stiffness. This is followed by anxiety.

Chart four outlines the top symptoms respondents think cannabis-derived products ease or may ease.

¹ Non-motor symptoms questionnaire, Chaudhuri KR, Martinez-Martin P, Schapira AHV, Stocchi F, Sethi K, Odin P et al (2006) ‘An international multicentre pilot study of the the first comprehensive self-completed non motor symptoms questionnaire for Parkinson’s disease: The NMSQuest study’ *Mov Disord*; 21(7):916-923 – <https://www.parkinsons.org.uk/sites/default/files/2017-12/Non-motor%20symptoms%20questionnaire.pdf> accessed 20 May 2019.

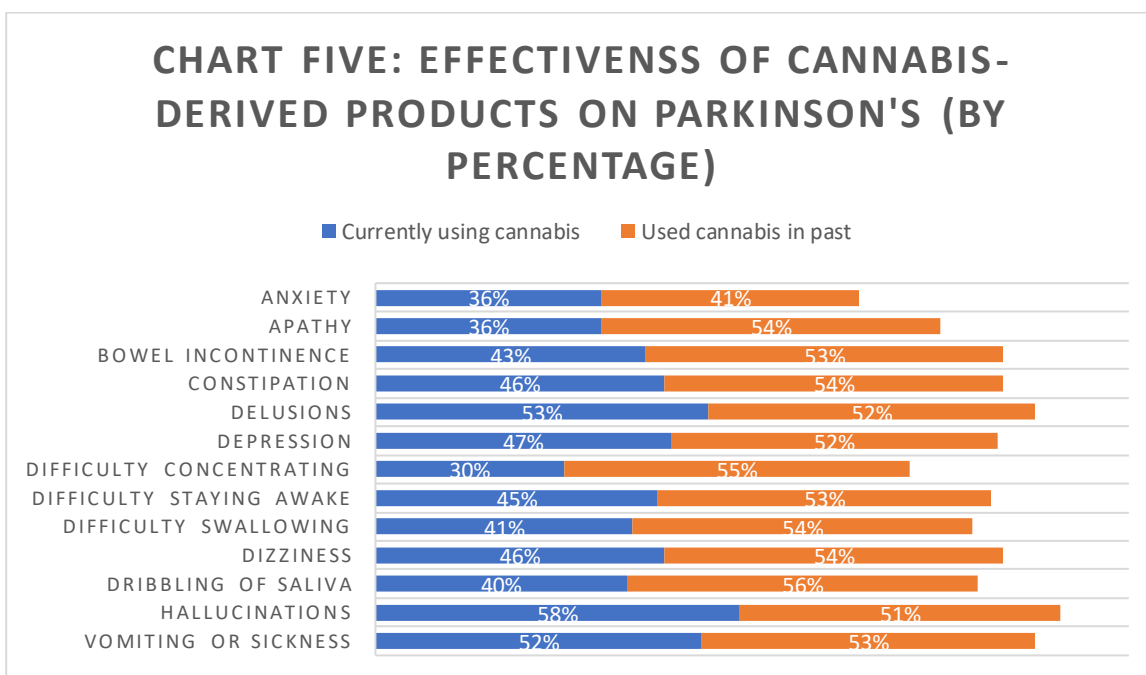


The most common symptoms that patients report to their care professionals as being eased by a cannabis-derived product are stiffness (reported by 48% of professionals), intense or vivid dreams (31%), difficulties concentrating (31%), slowness (24%) and constipation (21%).

Effectiveness of cannabis-derived products on Parkinson’s symptoms

We asked people with Parkinson’s who are currently using cannabis-derived products, or have used them in the past, to share which symptoms they think these products control most effectively.

We asked them to rate their effectiveness on a scale of one to five. We combined the responses for four and five to calculate which symptoms they believe the cannabis-derived products are the most effective at controlling.



However, professionals stated that they viewed cannabis-derived products as fairly limited in their effectiveness of controlling Parkinson's symptoms.

Side effects

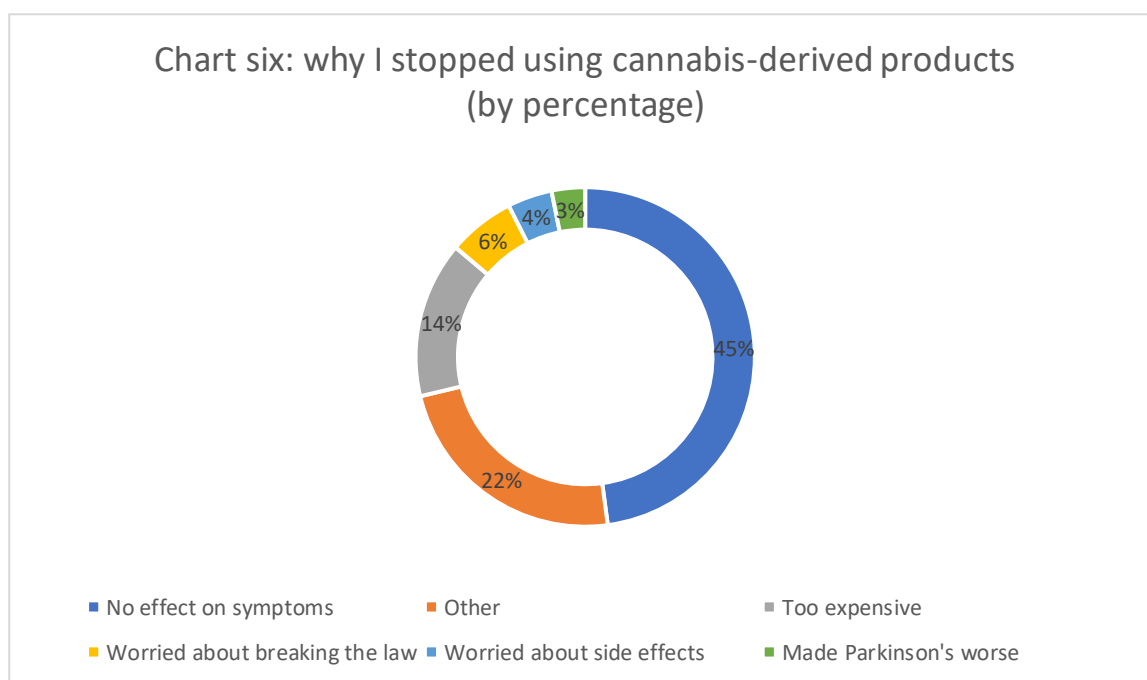
92% of people who are currently using a cannabis-derived product don't experience side effects. Of the 8% that do, they said these side effects include a feeling of worthlessness, a sore throat from smoking, feeling overmedicated alongside other Parkinson's medications, feeling high, being tired, having a slurry voice or feeling faint.

99% of people who currently use cannabis-derived products said that they don't think they affect their Parkinson's medication.

82% of people who have previously used cannabis-derived products didn't experience side effects. Of the 18% that did experience side effects, they said that the effects included being tired and feeling more lethargic, feeling dizzy or faint, being more anxious and paranoid, suffering from more panic attacks, feeling high, experiencing extreme tremors, headaches and sickness.

It is understandable that respondents who used cannabis-derived products in the past reported a higher number of side effects, and this could be one of the reasons that they stopped using them.

Chart six shows why respondents who previously used cannabis-derived products stopped taking them.



Responses from those who selected 'other' included:

- not being sure where to get it
- it being too complicated to make up the preparation
- being unsure of the correct dosage or quantity needed
- no evidence that it helped symptoms
- too costly
- it's ineffective
- the side effects outweigh the benefits

54% of respondents who haven't used cannabis-derived products in the past, but are interested in doing so in the future, said they have concerns about side effects. They are concerned about them impacting on their mental health or memory, increasing falls, and interacting with their existing medication. They are also concerned about not knowing what impact the products may have,

getting addicted, and the products making their freezing worse or increasing cognitive problems and hallucinations.

31% of professionals said their patients reported no side effects. 21% didn't know if their patients experienced side effects. Of the 48% of professionals who reported some side effects, these included dizziness, dry mouth, low blood pressure, nausea and psychomotor agitation, such as being unable to sit still, stiffness or feeling irritable.

Parkinson's medication and cannabis-derived products

40% of people who haven't tried cannabis-derived products said they think they will interact with their Parkinson's medication. Sinemet, Madopar and Stalevo are the most common drugs people are worried about. These are some of the most commonly prescribed Parkinson's drugs, so it's not surprising these are the ones most respondents are concerned about.

24 professionals reported that their patients using cannabis-derived products do not experience any interactions with their Parkinson's medications.

Advice from health professionals

59% of respondents who currently use cannabis-derived products, and 77% of respondents who have used cannabis-derived products in the past, said that they didn't speak to a health professional before they started using them.

For those respondents that did speak to a professional, they ranked them in the same order:

- their consultant
- their Parkinson's nurse
- their GP
- other (for instance surgeons, cardiologists, pharmacists, people living with long term conditions like MS and alternative therapists)
- allied health professionals (such as physiotherapists, occupational therapists or speech and language therapists)

66% of those currently using cannabis-derived products, and 44% of those who have used them in the past, shared that they found the professional's advice helpful.

86% of people who haven't used cannabis-derived products, but are interested in doing so, haven't spoken to a professional. Of those that have spoken to a professional, 62% stated that the professional's advice did not help them.

93% of professionals who responded said that their patients with Parkinson's do ask them about using a cannabis-derived product. Parkinson's nurses taking part in the survey are the professional most often asked about using a cannabis-derived product.

30% of professionals who responded haven't offered any advice on cannabis-derived products to their patients, while 70% have. The most common advice they offer is:

- Don't use it, as we don't have enough evidence on its effectiveness.
- Continue using it, but if you see any changes stop immediately and seek advice.

Other advice includes:

- Don't stop taking prescribed Parkinson's medication.
- Get it from reputable sources.
- Check in with your pharmacist to ensure it doesn't interact with your Parkinson's medication.

86% of professionals that responded said they don't feel confident in prescribing licensed cannabis-derived products. 61% (of the 28 professionals answering) said they don't know if current prescribing guidance is fit for purpose.

NHS England commissioned prescribing advice for cannabis-derived products for professionals from the British Paediatric Neurology Association, the Royal College of Physicians and the National Institute of Health and Care Excellence. This latter guidance won't be available until October 2019 at the earliest.

Future use of cannabis

97% of people currently using a cannabis-derived product said they will continue to use it, as it eases their symptoms. 95% said that if a cannabis-derived product becomes available to treat their Parkinson's they would be happy to add it to their medication regime.

"We need to understand which symptoms it is proven to assist with and at what dosage is safe etc."

"I'll try anything to alleviate my aches, pains and stiffness."

"It works better for me than conventional drugs."

"Because it's natural."

"Because anything is worth trying."

"Would be easier to get via a prescription than having to source an illegal product."

"Because no one product suits all, there are so many different products out there and it is very difficult to determine a reputable source and different strengths to suit. I would have no confidence that any government would make a single product of sufficient strength and ingredients as pureness of plant to be of help. It is a minefield."

"I would try anything to alleviate symptoms and slow the progress."

"There is a need to have more options to manage symptoms."

"Any drug that is proved to be effective without any serious side-effects is worth seriously considering."

"Better CBD sourced from regulated outlets rather than an unknown source."

"I'm on maximum levodopa, I'm too old for surgery and the pain can be severe and unmanageable now."

"Because it's likely to be regulated and produced to medical standards."

"If it works why not, it has given me a boost."

Selection of quotes from people with Parkinson's who are currently using cannabis-derived products.

92% of people who have used a cannabis-derived product in the past said that if one becomes available for Parkinson's they would want to use it to help control their symptoms.

"Don't know that it worked for me."

"Anything that helps with my Parkinson's symptoms is worth trying."

“Think there're less side effects and it's more effective than what's currently available.”

“Because I want to live, not exist, and carry on doing as much as possible. I’m 54, feel 94, and treated like I’m a drain to society.”

“Why not? Nothing else works very well.”

“If it is stronger than the stuff over the counter and prescribed, and if it could replace some of the PD drugs I have to take, then I probably would try it.”

“Willing to try anything that alleviates symptoms.”

“I would be prepared to give it another try if further research was carried out and perhaps strength increased.”

“To improve my quality of life, but only if the drug was legal. I'm already on so many medications that seem to become more ineffective now Parkinson's progresses.”

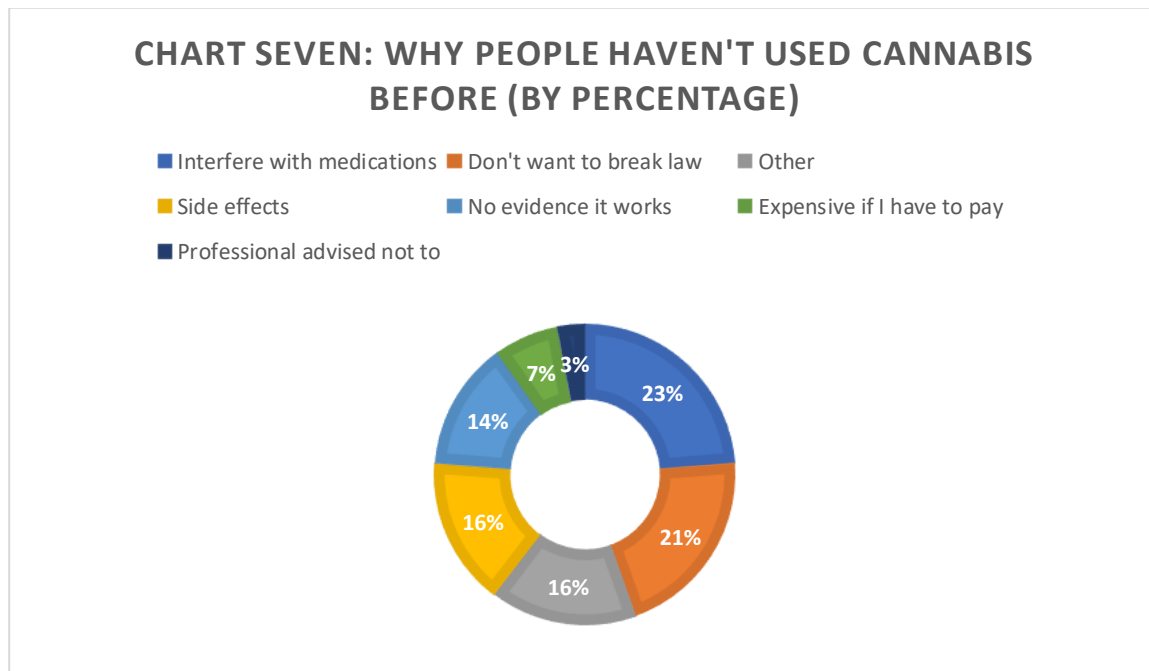
“If the guesswork were to be removed, I'd be willing to see if it helped.”

“Only if any consultant advised me to.”

“If it is proven effective for Parkinson's I would give it a go.”

Selection of quotes from people with Parkinson’s who have used cannabis-derived products in the past.

Chart seven shares the reasons why respondents haven’t used a cannabis-derived product before.



Other responses included:

- availability
- don't know enough about cannabis-derived products
- don't know where to get it
- no advice sought from a health professional yet
- can't get it on the NHS

- waiting for a clinical trial
- more research on its effectiveness needed
- not at the right stage in the condition to take it
- need to know the pros and cons
- not been given any advice on it
- currently not taking medications so might be useful later on in the journey

98% of respondents who have never used a cannabis-derived product before (either recreationally or for their Parkinson's) are interested in using one if it becomes available for the condition in the future.

"Current treatment has severe side effects."

"More natural product with possibly fewer side effects, more readily available and cheaper from smaller (local) companies."

"Why would you not try something that may help?"

"I would like to judge for myself if it helped me in any way."

"I might consider it if my consultant recommended it and there had been sufficient research into its effectiveness and possible side effects."

"Not instead of my PD medication, as well as."

"Only if it is tested and proved to be of benefit to people who suffer from parkinsonism."

"If the side effects are less than traditional Parkinson's drugs, then I would want to try cannabis."

"I am interested in looking at any new ways to treat the symptoms of Parkinson's."

"When needed but not right now."

"But only if my health professional agrees it would be worth taking the risk, and it may slow the progression and reduce my symptoms."

"My tremor is resistant to other drugs, and the cannabis is supposed to have a wide range of helpful effects."

"Current medication is not perfect."

"It could be taken as a complementary medicine."

"Because present medication is becoming less effective with time."

Selection of quotes from people with Parkinson's who have never used a cannabis-derived product.

69% (of the 29 prescribers answering) said they would consider prescribing a cannabis-derived product for their patient if the evidence shows it is safe and effective for treating Parkinson's symptoms.

Conclusion

People with Parkinson's want effective treatments to control their symptoms. Current medication doesn't have a lasting impact on many of the symptoms of Parkinson's. This is why one of our priorities is to speed up the discovery of better treatments and a cure.

Some people living with the condition have sought out other treatments to ease their symptoms, including cannabis-derived products.

Many have seen benefits from these products. But there is little scientific evidence that cannabis-derived products ease a person's Parkinson's symptoms.

The findings show that there is interest from people with Parkinson's in using cannabis-derived products, if more evidence of their safety and effectiveness is available.

This means there needs to be more research into understanding the impact of cannabis-derived products on Parkinson's symptoms.

We know there is a more comprehensive evidence base that cannabis-derived products can assist people living with MS, for example, around pain, stiffness and muscles spasms. Cannabis-derived products are also used to treat a rare form of childhood epilepsy, reduce sickness and vomiting in chemotherapy patients, and relieve pain.

With such interest from the Parkinson's community, it is important we encourage researchers to conduct work in this area to explore whether these products do have an impact on Parkinson's symptoms.

Many people living with the condition don't feel they have enough information to start using cannabis-derived products, with many stating that professionals have been unhelpful in their decision-making process.

Most professionals who responded said they would be happy to prescribe cannabis-derived products if there is robust evidence of their effectiveness in treating Parkinson's and clear treatment guidelines.

Therefore, there are some clear areas for Parkinsons' UK to focus on in the coming months. These include:

- producing our policy position on Parkinson's and cannabis
- calling for more clinical studies into the impact of cannabis on Parkinson's symptoms
- producing information resources and guidance on the use of cannabis-derived products
- engaging with the government to ensure they include Parkinson's in any future legislative changes, including issuing clearer treatment guidelines