

Personal Account of Medical Use of Cannabis

Clare Hodges

SUMMARY. The author provides a personal account of her sojourn with multiple sclerosis and its treatment with smoked and oral preparations of cannabis.

Additional information is provided as to the effects, dosing and delivery of cannabis employed by 250 members of the Alliance for Cannabis Therapeutics. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.HaworthPress.com>> © 2002 by The Haworth Press, Inc. All rights reserved.]

KEYWORDS. Cannabis, medical marijuana, multiple sclerosis, patient advocacy

I discovered I had multiple sclerosis (MS) 18 years ago when I was 25 years old. For several years I was only mildly affected. I carried on working as a television producer, married and had two children. Slowly my condition became worse, so that now I am constantly uncomfortable and tired. I am visually impaired and cannot sleep, eat or move very well.

Multiple sclerosis (MS) is a cruel disease. It develops when you're young and healthy, and slowly but surely you lose all your faculties, abilities and

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[Haworth co-indexing entry note]: "Personal Account of Medical Use of Cannabis." Hodges, Clare. Co-published simultaneously in *Journal of Cannabis Therapeutics* (The Haworth Integrative Healing Press, an imprint of The Haworth Press, Inc.) Vol. 2, No. 3/4, 2002, pp. 155-160; and: *Women and Cannabis: Medicine, Science, and Sociology* (ed: Ethan Russo, Melanie Dreher, and Mary Lynn Mathre) The Haworth Integrative Healing Press, an imprint of The Haworth Press, Inc., 2002, pp. 155-160. Single or multiple copies of this article are available for a fee from The Haworth Document Delivery Service [1-800-HAWORTH, 9:00 a.m. - 5:00 p.m. (EST). E-mail address: getinfo@haworthpressinc.com].

functions. Nowadays you can often expect to live your full life span until you become completely dependent, and of course this is a very depressing prospect. I began to get gloomy and introspective, as all my future seemed to hold was deteriorating health, since I had not found any medicines that really helped.

The medicines prescribed only gave limited relief and often with unacceptable side effects. Over the years I've been given steroids, tranquilisers, pain-killers, muscle relaxants and antidepressants. At best they only helped in the short term, and many have intolerable side effects. My main problem, however, was that my bladder was in constant spasm and no prescribed medicines helped me. For several months I took oxybutinin to help my bladder. This didn't help the problem, but I persevered, hoping at some time it might. However, it gave me side effects of blurred vision and headaches. My nights were so disturbed by the bladder problems, I was given temazepam to help me sleep, which did get me off to sleep, but left me slow and 'hung-over' the following day. Using cannabis helped me gradually cut back on these medicines, so that I stopped oxybutinin, and cut down on temazepam. I much preferred using cannabis because not only did it seem just as effective, but also I felt I had control over my medication, which was very important.

In 1992 I read an article in a U.S. journal about how some doctors had observed cannabis could help people with MS. Before I did anything I talked to different doctors I saw. None of them knew much about it, but said they thought it wouldn't do me much harm in moderate quantities, and indeed it was probably safer than many of the medicines they could prescribe.

As I was a middle class mother of two very young children I had a bit of a problem obtaining cannabis. My life revolved around the local mothers and toddlers group and it was sometimes quite embarrassing asking people if they could assist me, but eventually I found someone who did help me get some and showed me how to use it. I had approached a woman I knew from when I was working who I'd been told used cannabis. I didn't know her very well, but decided to ask her for help. Like most people, she was happy to help someone in trouble, and came around one evening when the children were in bed. She brought some cannabis, tobacco and papers, and showed me how to roll a joint. She smoked some with me, talking me through what I might be experiencing, constantly telling me to take it slowly. I'd tried cannabis about twice when I was a student, but without much effect, so I was very naïve. I had smoked cigarettes for a few years when I was younger, and still have an occasional cigarette, so smoking tobacco was familiar to me. The advice she gave to go slowly was very good, as I now know it is easy to take too much if you're not careful.

When I did try cannabis, the physical relief was almost immediate. The tension in my spine and bladder was eased, and I slept well. I was comfortable with my body for the first time in years. Just as important, I felt happy that

there was something, after all, that could help me. It was as if a huge weight had been lifted from me.

My MS symptoms vary considerably. Sometimes I can appear very well, and at other times I look and sound very handicapped. Similarly, I can be cheerful about my situation, but when the MS is bad I become very introspective and gloomy. Very simple tasks take enormous effort and leave me exhausted. Cannabis helps to stabilize my health and I find I can now do simple things that I hadn't been able to do, like go to the shops, or cook my children's dinner after school.

It took a couple of months to work out how to self-medicate. The main problem, which continues to this day, is working out how to use each new batch as strength and quality differ considerably. To begin with, it was easy to take too much or too little. If I took too much I became uncoordinated and confused, which distressed me and made it harder to deal with the condition. I have now established a routine that helps. I take 9 grams of herbal cannabis per week, drinking it in milky drinks during the day, and smoking it at night before I go to bed. To make the drink, I simmer the cannabis in milk for a few minutes, sieve the milk to remove the leaves, then drink the milk. I do not smoke it with tobacco, but dried herbs in a herbal tobacco mix you can buy in health food shops. I've found smoking is the easiest way of taking it to treat my disease, as it is much easier to regulate the dose. MS is a particularly unpredictable disease, not just in the long term, but from day to day, and almost hour to hour. Over 24 hours I would usually expect to take 4 joints (half cannabis, half herbal tobacco). However, the total number can be only two, or up to six or seven, depending on the state of health.

So, it's vitally important that MS patients have some kind of control over when and how much of the medicine they take, in the same way that patients often self-titrate for pain relief.

There was concern expressed by politicians and charities when medical use of cannabis was first talked about, that patients would become addicted to cannabis and would be tempted to take 'harder' drugs. I've never been able to take this very seriously, but I thought I'd say that I don't feel in any way addicted to cannabis. If for some reason I can't use it (such as when travelling abroad), I don't crave it or suffer withdrawal symptoms; the MS simply gets worse.

I've been prescribed nabilone, the only available cannabinoid preparation currently available in Britain. I took 1 mg daily for four nights, but it made me confused and clumsy. I persevered for four days, hoping it might be a substitute, but it wasn't. It's not clear to me whether a synthetic preparation will ever have the same therapeutic benefit as the natural plant.

My neurologist was very impressed by how much better I was. He put me in touch with two other patients with MS who also used cannabis. When we found out that cannabis in tincture form was available by medical prescription

in Britain until 1973, we decided to start an organisation based on the U.S. Alliance for Cannabis Therapeutics (ACT) to press for cannabis to be moved from Schedule 1 to Schedule 2 and thereby restore it as a legal medicine. It has involved an enormous amount of work, dealing with thousands of letters from patients, doctors and politicians. The ACT has never pressed for legalisation of cannabis and has no 'hidden agenda.' I've always thought a great strength of our group is that it's been run and financed entirely by patients. We do not fund-raise nor have we applied for charitable status, but have remained quite independent. It was doubtless thanks to our independent status that official bodies have regularly consulted the ACT.

We were very involved in the British Medical Association report and were interviewed by the House of Lords Select Committee on cannabis. Led by Austin Mitchell, MP, we took two delegations of patients and doctors to talk to the Ministers of Health and the Home Office. These delegations were very distinguished, including Lord Whaddon, who suffers from MS, and Professor Patrick Wall, the specialist in pain control.

In 1997 we invited the director of a pharmaceutical company, GW Pharmaceuticals, to join our delegation when the doctors and politicians representing the ACT asked the Department of Health Minister, Paul Boateng, if his company could be granted a licence to grow cannabis for medical research. This was issued shortly afterwards and clinical trials are now proceeding with a preparation manufactured by the company and administered via a sublingual spray. Following this, the Medical Research Council has set up several trials around the country, using synthetic versions of cannabis.

I've been using cannabis for nine years. There is no doubt that my condition has improved in different ways. I do not have to take as many prescribed medicines. I now eat better, sleep better, and I feel more positive and motivated.

GENERAL OBSERVATIONS FROM PATIENTS

I've outlined my personal experience of using cannabis with MS, but I'm also in a position where I can give a broader overview as over the last nine years I've talked to or corresponded with many patients who use cannabis. Of the 3,000 letters the ACT has received, there are about 250 patients who have written about their use of cannabis in some detail. There have been more letters from women than men, and they have tended to be older rather than younger. I assume this reflects the general pattern of people with MS. Although most women are early or late middle-aged, a handful of much older people (70+) have also written about their experiences. Several of these I have followed up by visiting and talking to the people who wrote in.

Here are some thoughts I now want to pass based on these letters and conversations over the years.

PSYCHOACTIVITY

There is a recurring theme through all the letters patients write: cannabis helps them because it not only eases their physical problems, but also improves their mood, lifts their spirits, and gives them a better quality of life.

There's a large literature about the effects of cannabis, but when you're chronically ill your experience of all these effects is somewhat different.

Like all medicines and drugs cannabis has a mixture of physical and psychoactive effects. One common physical effect is that it relaxes muscles, which is one reason why people enjoy using it, but when you have MS relaxing muscles is not just fun—it is very important. For many of us it takes much effort and concentration just to move around and do ordinary things. I know this makes me slightly tense all the time which is very wearing and uncomfortable and can result in going into spasm. So relaxing muscles is not just a way of 'chilling out,' but can mean people are able to function more normally.

Similarly, the more I talk to ill and disabled people who use cannabis, the more I think the psychoactive effects are vital to its therapeutic value. There's been great interest in developing drugs that will affect the physical progress of the disease, but for many sufferers and their families being depressed and demoralised is the hardest aspect of the disease to live with and can be extremely debilitating. In the same way that your physical strength diminishes, your mental powers and spirit weaken. One person who wrote to our group put the benefits of the psychoactive effects very well. He said that "people in good health who smoke cannabis get high, while if you've got MS, you're under par all the time, you don't move properly, see properly, have much energy, and cannabis lifts you to normality."

It has been slightly disheartening when some people say we need to find a version of cannabis without the psychoactive effects. This could only work well for a type of MS that produces no psychological effects. The effort to eliminate mood-altering effects seems to me to be a fundamental misunderstanding of how it helps us.

DELIVERY METHODS

Most people choose to smoke cannabis, for the reasons I've mentioned, but many don't like smoking. I've been very impressed by how inventive people are about how to take the cannabis. Two of the people I went to see in the Orkney Islands have developed a skin patch. They simply put some home-grown

cannabis on their skin and cover with cling film and a surgical waterproof bandage. They say this gives them a regular, low dose of cannabis that keeps them going for a couple of days. Several people bake it in cakes, but often have a problem as they don't know how it is distributed. I went to see a lady in my home county, Yorkshire, who has got around this by baking little buns with just a tiny pinch in each bun. This simple, neat solution really appealed to me. Someone else has tried to use it as a suppository, but seemed very primitive. This lady with MS did not continue with the suppositories, finding smoking much easier, if more wasteful.

DOSAGE

It is remarkable the very different amounts people use to find relief. For some, an ounce of herbal cannabis may last four months, for others only two weeks. Similarly the amount used can vary considerably in the same patient. Research could be more flexible in amounts tested on patients, acknowledging the unpredictability of the disease.

In general, patients who use cannabis now outside the law are a rich source of information. Their experiences could help direct any further research.