

A Novel Approach to the Symptomatic Treatment of Autism

Parents of some autistic children report that cannabis eases behavioral problems more effectively than conventional pharmaceuticals. Their anecdotal evidence should be taken seriously by medical researchers.

by Lester Grinspoon M.D.

Autism is one of a group of conditions known as pervasive developmental disorders. This mysterious disability, first described and named more than 60 years ago, is characterized by striking emotional and cognitive isolation and detachment.

Autistic children are characterized by their apparent inability to form human relationships, abnormal or absent speech, and an unusually limited range of activities and interests. It is estimated that three to six out of every 1000 children in the United States has autism, about three quarters of them are boys, and the number of cases appears to be rising. It is not clear whether this is due to better detection and reporting of autism, a real increase in the prevalence, or both.

While symptoms of autism often occur in the first months of life, they may be disregarded at first, but by the age of two or three it is clear that something is seriously wrong. Autistic children show little interest in others, children or adults. They do not communicate experiences and there is little if any spontaneous or imaginative play; instead they prefer monotonous, solitary activities. They may spend hours performing ritualistic repetitive motions. They can be fascinated by one limited subject or activity to the exclusion of all others and they are sometimes violent in their resistance to efforts to change the focus of their attention. They appear to fear novelty and may explode in rage when faced with change.

Many autistic children are hypersensitive to minor noises, smells and physical sensations, and some are hyperactive, impulsive, aggressive and self-destructive. They may throw tantrums in response to apparently trivial frustration, repeatedly bite themselves, hit themselves with their fists, or strike their heads against a wall. Their language develops slowly and in an odd way, making them unintelligible; some do not speak at all. The vast majority, but not all, are retarded. A few, who may or may not be retarded, have unusual talents; they are known as savants.

There is no cure for autism, nor is there "one-size-fits-all" treatment. Treatment options include behavior and communication therapies, educational therapies and drug therapies. Our interest here is in exploring the possibility of a new drug therapy.

Drugs have a place in treating autistic symptoms, but their uses are limited. Antipsychotic drugs and mood stabilizers may help autistic patients who repeatedly injure themselves. The older conventional antipsychotic drugs have serious side effects on body movements. The novel or atypical drug risperidone (Risperdal) has shown a glimmer of promise in recent research. Anticonvulsants may be useful in suppressing explosive rage and calming severe anxiety. About 20% of autistic people have epileptic seizures, and some researchers have suggested that unrecognized partial complex seizures, which cause changes in consciousness but not muscular convulsions, are one source of autistic behavior disturbances.

In several studies, selective serotonin reuptake inhibitors (SSRIs) have been found to relieve depression and anxiety and reduce compulsive ordering, collect-

ing, and arranging. Unfortunately, little is known about the long-term effects of drugs in autistic children, and no known drug has any effect on the underlying lack of capacity for empathy and communication.

A Mother's Report

With the explosive growth of interest in exploring the medicinal capacities of marijuana, some courageous parents, concerned about the toxicity of the above-mentioned drugs, and desperate to find pharmaceutical means of relieving their children of some of the harsh symptoms of autism, have been experimenting with oral doses of cannabis. The following anecdote was provided by Marie Myung-Ok Lee who teaches at Brown University. She is the author of the novel *Somebody's Daughter* and is a winner of the Richard Margolis award for social justice reporting.

"My son J, who is nine years old, has autism. He's also had two serious surgeries for a spinal cord tumor and has an inflammatory bowel condition, all of which may be causing him pain, if he could tell us. He can say words, but many of them don't convey what he means.

"J's school called my husband and me in for a meeting about J's tantrums, which were affecting his ability to learn. Their solution was to hand us a list of child psychiatrists. Since autistic children like J can't exactly do talk therapy, this meant sedating, antipsychotic drugs like Risperdal (risperidone).

"As a health writer and blogger, I was intrigued when a homeopath suggested medical marijuana. Cannabis has long-documented effects as an analgesic and an anxiety modulator. Best of all, it is safe. A publication by the Autism Research Institute described cases of reduced aggression, with no permanent side effects.

"After a week on Marinol, which contains a synthetic cannabinoid, J began garnering a few glowing school reports. But J tends to build tolerance to synthetics, and in a few months, we could see the aggressive behavior coming back. One night, at a medical-marijuana patient advocacy group, I learned that the one cannabinoid in Marinol cannot compare to the 60 in marijuana the plant.

"Rhode Island, where we live, is one of 14 states where the use of medical marijuana is legal. And yet, I hesitated. Now we were dealing with an illegal drug, one for which few evidence-based scientific studies existed precisely because it is an illegal drug. But when I sent J's doctor the physician's form that is mandatory for medical marijuana licensing, it came back signed. We underwent a background check, and J became the state's youngest licensee.

"The coordinator of our medical marijuana patient advocacy group introduced us to a licensed grower, who had figured out how to cultivate marijuana using a custom organic soil mix. The grower left us with a month's worth of marijuana tea, glycerine, and olive oil — and a cookie recipe. We paid \$80.

"We made the cookies with the marijuana olive oil, starting J off with half a small cookie. J normally goes to bed around 7:30 p.m.; by 6:30 he declared he was tired and conked out. As we anxiously peeked in on him, half-expecting some red-eyed ogre from Reefer Madness to come leaping out at us, we saw instead that he was sleeping peacefully. Usually, his sleep is shallow and restless.

"When J decided he didn't like the cookie anymore, we switched to the tea. After two weeks, we noticed a slight but consistent lessening of aggression. Since we started him on his 'special tea,' J's face, which is sometimes a mask of pain, has softened. He smiles more. For the last year, his individual education plan at his special-needs school was full of blanks because he spent his whole day in an irritated, frustrated mess. Now, April's report shows real progress, including "two community outings with the absence of aggressions."

"The big test has been a visit from Grandma. The last time she came, J hit her. This time, she remarked that J seems calmer. As we were

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preparing for a trip to the park, J disappeared, and we wondered if he was going to throw one of his tantrums. Instead, he returned with Grandma's shoes, laying them in front of her, even carefully adjusting them so that they were parallel. He looked into her face, and smiled.

"It's strange, I've come to think, that the virtues of such a useful and harmless botanical have been so clouded by stigma. Meanwhile, in treating J with pot, we are following the law — and the Hippocratic oath: first, do no harm. The drugs that our insurance would pay for — and that the people around us would support without question — pose real risks to children. For now, we're sticking with the weed.

"How is J doing now, four months into our cannabis experiment? Well, one day recently, he came home from school, and I noticed something really different: He had a whole shirt on.

"Pre-pot, J ate things that weren't food. He chewed the collar of his T-shirts while stealthily deconstructing them from the bottom up, teasing apart and then swallowing the threads. His chewing become so uncontrollable we couldn't let him sleep with a pajama top (it would be gone by morning) or a pillow (ditto the case and the stuffing). The worst part was watching him scream in pain on the toilet, when what went in had to come out.

"Almost immediately after we started the cannabis, this stopped. Just stopped. J now sleeps with his organic wool-and-cotton, temptingly chewable comforter. He pulls it up to his chin at night and declares, 'I'm cozy!'

"Next, we started seeing changes in J's school reports. At one August parent meeting, his teacher excitedly presented his June-July 'aggression' chart. For the past year, he'd consistently had 30 to 50 aggressions in a school day, with a one-time high of 300. The charts for June through July, by contrast, showed he was actually having days — sometimes one after another — with zero aggressions.

"I don't consider marijuana a miracle cure for autism. But I do consider it a wonderful, safe botanical that allows J to participate more fully in life without the dangers and sometimes permanent side effects of pharmaceutical drugs, now that we have a good dose and a good strain. Free from pain, J can go to school and learn. And his violent behavior won't put him in the local children's psychiatric hospital — a scenario all too common among his peers.

"We have pictures of J from a year ago when he would actually claw at his own face. That little child with the horrifically bleeding and scabbed face looks to us now like a visitor from another world. The J we know now just looks like a happy little boy.

"We worried that 'the munchies' would severely aggravate J's problems with overeating in response to his stomach pangs. Instead, the marijuana seems to have modulated these symptoms. J still can get over-excited if he likes a food too much, so the other day, we dared to experiment with doengjang, a tofu soup

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Lester Grinspoon, MD, Associate Professor Emeritus of Psychiatry at Harvard Medical School, was the first U.S. doctor to prescribe lithium carbonate for bipolar disorder. While writing *Marihuana Reconsidered* (Harvard, 1971) he became convinced that the plant was beneficial. *Marihuana: The Forbidden Medicine* (with James Bakalar, Yale, 1997) lists its wide range of applications.

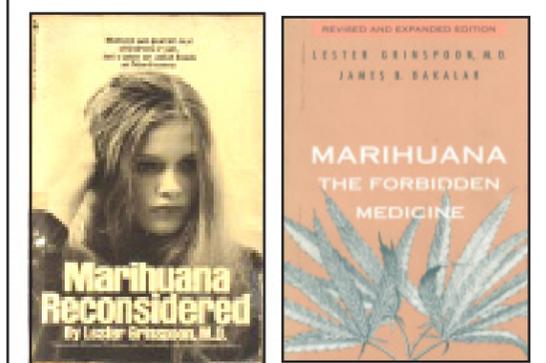


photo by George Heyer

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that he used to love as a baby. The last time we tried it, a year ago, he frisbeed the bowl against a tile wall.

"We left J in the kitchen with his steamy bowl and went to the adjoining room. We heard the spoon ding. Satisfied slurpy noises. Then a strange noise that we couldn't identify. A chkkka bssshhht doinnng! We returned to the kitchen, half expecting to see the walls painted with doenjang. Everything was clean. The bowl and spoon, however, were gone.

"J had taken his dishes to the sink, rinsed them, and put them in the dishwasher —something we'd never shown him how to do. In four months, he'd gone from a boy we couldn't feed to a boy who could feed himself and clean up after. The sight of the bowl, not quite rinsed, but almost, was one of the sweetest sights of my parental life. I expect more to come."

Because autism is such a devastating and so far incurable disease, and the available pharmaceutical products have such limited usefulness and serious side-effects, anguished parents like Marie Myung-Ok Lee seek out alternative therapies.



I have had the opportunity to consult with and help a small number of these parents explore marijuana as a medicine which can help to control some of the severe behavioral problems. (For the approximately one in five children with autism who suffer some sort of seizure disorder, it is important to note that marijuana is an excellent anticonvulsant and was widely used as such in the last part of the 19th century and the early decades of the 20th). Those who have persevered in the arduous process of both finding the correct oral vehicle and titrating the optimal dose have been rewarded in more or less the same ways as J's parents.

The first obstacle in the path of anyone who wishes to explore cannabis as a medicine is to overcome the widely held belief that it is a very dangerous substance. The misinformation campaigns of the United States government and such organizations as the Partnership for a Drug-Free America notwithstanding, marijuana is an unusually safe drug. In fact, after federal-court-ordered lengthy hearings before a Drug Enforcement Administration Law Judge involving many witnesses, including both patients and doctors, and thousands of pages of documentation, Judge Francis L. Young in 1988 asserted that "marijuana, in its natural form, is one of the safest therapeutic active substances known to man..."

Cannabis was much used in Western medicine from the mid-19th century until shortly after the passage of the Marijuana Tax Act of 1937. There has never been a recorded death attributable to marijuana. When it regains its rightful place in the US pharmacopeia, it will soon be recognized as one of the least toxic medicines in that compendium. While there are no studies of the toxicity of cannabis in children, neither are there pediatric studies of the toxicity of risperidone and other conventional drugs used in the treatment of autism. However, to the extent that one can extrapolate the adult toxicity profiles of the antipsy-

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chotic drug risperidone and cannabis, the latter is the much safer drug.

It is often objected, especially by federal authorities, that the medical usefulness of marijuana has not been demonstrated by controlled studies, the rigorous, expensive, and time-consuming tests necessary to win approval by the Food and Drug Administration (FDA) for marketing as medicines. The purpose of the testing is to protect the consumer by establishing both safety and efficacy. Because no drug is completely safe (nontoxic) or always efficacious, a drug approved by the FDA has presumably satisfied a risk-benefit analysis.

The cost of doing the controlled studies necessary for FDA approval may run to about \$800 million per drug, a cost borne by the drug company seeking it as a necessary pre-requisite for the distribution of its patented product. Because it is impossible to patent a plant, pharmaceutical companies are not interested in developing this herbal medicine and so far the cannabinoid products they have developed are not nearly as useful as whole herbal marijuana.

Should FDA Rules Apply?

But it is doubtful whether FDA rules should apply to marijuana. First, there is no question about its safety. It has been used for thousands of years by millions of people with very little evidence of significant toxicity. Similarly, given the mountain of anecdotal evidence which has accumulated over the years, no double-blind studies are needed to prove marijuana's efficacy. Any astute clinician who has experience with patients who have used cannabis as a medicine knows that it is efficacious for many people with various symptoms and syndromes. What we do not know is what proportion of patients with a given symptom will get relief from cannabis and how many will be better off with cannabis than with the best presently available medicine. Here large, controlled studies will be helpful.

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Physicians also have available evidence of a different kind, whose value is often underestimated. Anecdotal evidence commands much less attention than it once did, yet it is the source of much of our knowledge of synthetic medicines as well as plant derivatives. Controlled experiments were not needed to recognize the therapeutic potential of chloral hydrate, barbiturates, aspirin, curare, insulin, or penicillin. Furthermore, it was through anecdotal evidence that we learned of the usefulness of propranolol for angina and hypertension, of diazepam for status epilepticus (a state of continuous seizure activity), and of imipramine for childhood enuresis (bed-wetting) although these drugs were originally approved by the FDA for other purposes. Anecdotes or case histories of the kind presented here by Marie Myung-Ok Lee are, in a sense,

the smallest research studies of all.

Anecdotes present a problem that has always haunted medicine: the anecdotal fallacy or the fallacy of the enumeration of favorable circumstances (counting the hits and ignoring the misses). If many people suffering from, say, muscle spasms caused by multiple sclerosis take cannabis and only a few get much better relief than they could get from conventional drugs, these few patients would stand out and come to our attention. They and their physicians would understandably be enthusiastic about cannabis and might proselytize for it. These people are not dishonest, but they are not dispassionate observers. Therefore, some may regard it as irresponsible to suggest on the basis of anecdotes that cannabis may help some people with a variety of symptoms and disorders. That might be a problem if marijuana were a dangerous drug, but it is becoming increasingly clear that it is remarkably safe. Even in the unlikely event that only a few autistic children get the kind of relief that "J" gets, it could be argued that cannabis should be available for them because it costs so little to produce, the risks are so small, and the results so impressive.

While federal law is absolute in prohibiting the use of marijuana for any purpose, beginning with California in 1996, there are now 14 states where it is possible to use it as a medicine within specified limits. California, in addition to being the first state to make an accommodation to patients in need of cannabis, is also one of the states in which the legal interpretation of those needs and the means by which they can be filled is broad enough to satisfy the demands of patients with the wide variety of symptoms and syndromes for which this herb is useful.

New Jersey, the latest state to adopt medical marijuana legislation, is, unfortunately, among the most restrictive. It is so restrictive both with respect to the symptoms and syndromes for which a patient is allowed to use the drug and the means by which patients are allowed access to it, that only a relatively small percentage of the patients who would find marijuana more useful, less toxic, and less expensive than the conventional drugs they presently use will have access to it. Fortunately for her and her family, Marie Myung-Ok Lee lives in Rhode Island, where after presenting the appropriate credentials from J's physician, she was licensed to legally obtain marijuana. However, in most states patients or the people responsible for their care have to make, what for many of them, is a very difficult decision —whether to buy or grow cannabis outside of the law.

Beyond gaining access to marijuana, there are the problems involved in the preparation of this medicine in a form suitable for children. The most common way in which marijuana is used as a medicine is through inhalation of the smoke from a pipe, a joint or a vaporizer. This is the preferred method for adults, because it makes it possible for the patients to precisely titrate the dose because with this method of delivery they will perceive the therapeutic effects within minutes. However, inhalation is not an option for children who suffer from autism; for these patients, the best route for administration is oral, in the form of cookies, brownies, tea, etc.



There are now available marijuana cookbooks from which a variety of edibles which appeal to children can be found. (See article at right) With ingestion, the therapeutic effects will not appear before one and a half to two hours, but the advantage is that they last for many hours.

Beyond preparing the edible are the challenges of determining the right dose (such as beginning with a fraction of a cookie and increasing the dose as needed) and establishing a schedule for taking the medication. These tasks will require some experimentation on the part of the parents, but with experience they will soon find the best recipes for their child, the ideal dose and a workable schedule. Unfortunately, because there is presently no easy and available way of knowing with any precision the potency of any particular batch of marijuana, each newly prepared edible will have to be re-titrated, but with experience caregivers will find this an increasingly less difficult task. It is also important to remember that cannabis is a very forgiving medicine; one would have to be considerably over the "ideal" dosage mark to cause any difficulty.

One way of minimizing what are usually minor therapeutic differences between one batch of cannabis and another is to try to use the same strain of marijuana every time an edible is prepared. At the same time, many patients who use marijuana as a medicine take advantage of the fact that there is a growing variety of available strains, each with slight differences in the percentages and ratios of the different therapeutic cannabinoids. This allows patients to empirically explore the different strains in an effort to identify the particular strain which appears to be the therapeutically most useful for their symptomatology.

The parents of autistic children carry a heavy burden. They are constantly challenged and frustrated by the child's inability to communicate, his impulsiveness and his destructive and self-destructive behavior. They and other caregivers become emotionally drained and physically exhausted from the constant need for supervision. It is my hope that this paper will bring to the attention of many of these parents the possibility that there may be a new, if not officially or even medically approved, approach to their daunting challenge. While this approach may not work for all, it assuredly will do no harm.

