

Cannabis as Therapy for People Living with HIV/AIDS:

“Our Right, Our Choice”

EXECUTIVE SUMMARY

Who We Are

The Canadian AIDS Society is a national coalition of more than 125 community-based AIDS service organizations across Canada. We are dedicated to strengthening the response to HIV/AIDS across all sectors of society, and to enriching the lives of people and communities living with HIV/AIDS.

Description of the Project

We received funding from the Public Health Agency of Canada to study the barriers to access to cannabis for medicinal purposes for people living with HIV/AIDS. We conducted an extensive consultation of people living with HIV/AIDS from across Canada through focus groups and a widely distributed questionnaire. This executive summary provides an overview of a policy paper¹ that outlines the barriers to access to the federal medical cannabis program, to a legal source of cannabis, and to adequate information and services. Recommendations are made to address these barriers so that people living with HIV/AIDS can treat themselves without fear of criminal prosecution, with a safe and affordable source of cannabis, with adequate information to make informed decisions, and with the necessary support to optimize their health.

“Our Right”

Legal, Regulatory and Policy Complexities

In Canada, cannabis (marijuana) remains a controlled substance subject to the *Controlled Drugs and Substances Act*, which prohibits possession, cultivation, trafficking, possession for the purpose of trafficking, importation and exportation.

Cannabis is a plant and would normally be considered a natural health product subject to the *Natural Health Products Regulations* were it not for its designation as a controlled substance. Law reform regarding personal adult use of cannabis has been considered in

“I believe strongly in the right for humans to have access to what nature provides. . . It's not for everybody but it's for me.”

“I believe we all have a right to our own therapy, whether it's medical marijuana or whether it's narcotics prescribed by our doctors.”

—Focus group participants

Canada but has yet to manifest. The only other option for herbal cannabis to become widely available for medical use would be for it to be subjected to the drug approval process. If approved as a drug, cannabis could then be prescribed by physicians and reimbursement of costs to seriously ill Canadians could be considered under provincial health insurance programs.

However, the approval of herbal cannabis as a drug is unlikely so long as a criminal prohibition on cannabis use is maintained. The drug approval process is governed by the *Food and Drug Regulations* (FDR). The typical process by which new drugs enter the therapeutic marketplace involves a “drug sponsor” who has identified a potentially therapeutic molecular compound from which the sponsor ultimately hopes to profit. Bringing a new drug to market is expensive, and both the criminal law and the law of intellectual property (i.e. patents on plant products) have served as disincentives for the initiation of drug development and approval by drug sponsors.

However, some pharmaceutical companies have shown an interest in developing cannabis-based products. The focus of research and development has been on synthetic derivatives, and in the next decade one may expect to see a variety of synthetic cannabis-based medicines on the market. Regardless of the availability of pharmaceutical products derived from cannabis, some seriously ill Canadians will continue to opt for herbal cannabis, thus the importance of addressing the barriers to access to the federal medical cannabis program.

Use of Cannabis for Medicinal Purposes

As many as 14% to 37% of people living with HIV/AIDS use cannabis to help manage symptoms such as appetite loss, wasting, nausea and vomiting, pain, anxiety, depression and stress, among others. It is also estimated that several thousand Canadians use cannabis for medicinal purposes for conditions such as multiple sclerosis, side effects of chemotherapy for cancer, severe pain due to arthritis or spinal cord injury or disease, seizures due to epilepsy and others.

The Federal Medical Cannabis Program

As a result of a legal challenge, our courts have ruled that a person has a constitutional right to access cannabis for medical purposes without fear of criminal prosecution, and that a person has the freedom to make decisions that are of fundamental personal importance without interference from the state. In response to this court decision, Health Canada introduced the *Marihuana Medical Access Regulations (MMAR)* in 2001, which enable compassionate access to cannabis for people who are suffering from serious illnesses and related symptoms. Canada is among a handful of countries that have made cannabis available to its seriously ill citizens. The learning curve has been steep and groundbreaking.

Barriers to Legal Access

Despite estimates that thousands of seriously ill Canadians use cannabis for medicinal purposes, only 1399 persons are currently legally authorized to possess cannabis for medical purposes. Only 26% of the medicinal users of cannabis we consulted had obtained an authorization to possess cannabis for medical purposes. Access to the federal program remains hindered by barriers such as a lack of awareness of the program’s existence, mistrust in the government, misinformation about the program and difficulty in finding a physician to support their application. Thousands of seriously ill Canadians must therefore choose between breaking the law to use the therapy of their choice, or going without, which in many cases compromises their well-being and quality of life.

Access to a legal, safe and affordable source of cannabis is also severely hindered due to the limited options available to people who obtain the legal authorization to possess cannabis for medical purposes. Access to adequate information and services related to this treatment is minimal to non-existent, making it difficult for people to make informed decisions about their therapy and to optimize their care.

The Medical Profession's Reluctant Participation

The medical community has been reluctant to participate in the federal medical cannabis program because of the lack of information it has regarding the medical use of cannabis. Until adequate research is conducted and the arduous drug approval process is undertaken, participation by physicians in the federal medical cannabis program will remain severely hampered. Drug approval would facilitate physicians' support of cannabis use, access to cannabis for medical purposes, and reimbursement of costs for medical users.

It is critical that clinical research be conducted, otherwise the federal medical cannabis program will remain a special access program rife with unnecessary regulatory and bureaucratic barriers. Special access programs are used extensively for physicians to obtain experimental drugs for people living with HIV/AIDS. They are designed to allow physicians to secure unapproved drugs for seriously ill patients. The application process requires physicians to outline why the unapproved drug is the "best choice" and whether other therapies have been "considered, ruled out and/or failed to achieve an adequate choice". The federal medical cannabis program is designed along the same lines.

Thwarting of Research

Prohibition has thwarted research into the therapeutic properties of cannabis in its herbal form. Researchers have been reluctant to initiate studies due to the burdensome regulatory and bureaucratic processes required to gain access to a legal source of cannabis with which to conduct their research, as well as the stigma associated with cannabis use, especially in smoked form.

More research is needed regarding the management of HIV/AIDS related symptoms with cannabis, cannabis versus pharmaceutical products, adherence to antiretroviral therapy, and long term effects of cannabis use. It is clear that more research is needed using cannabis in either smoked or vaporized form. Long-term studies on the effects of cannabis on the immune system and on antiretroviral medications, as

well as studies on the direct effects of cannabinoids on the CD4 cell counts and viral loads need to be conducted to determine the long term safety of cannabis use for people living with HIV/AIDS. The effects of different strains must also be studied.

Research can greatly be enhanced by involving community groups or organizations such as AIDS service organizations or compassion clubs, from the development of the research protocol to the dissemination of results from a clinical trial. An innovative approach to clinical trials entails creating a community advisory committee to obtain input directly from the population one wishes to study. Such a committee can also assist with recruitment. Community-based research also has an important role to play in contributing to the greater body of knowledge.

"Our Choice"

Limited Choices of Product

Despite the existence of the federal medical cannabis program and of the MMAR, legal choices for authorized persons to have access to a safe and affordable source of cannabis remain severely limited: they can purchase the cannabis grown by the government, they can purchase seeds from the government and grow their own cannabis, or they can designate a person to grow for them and only them. The majority of the people we consulted relied on illegal sources for their supply of medicinal cannabis: 62.5% of respondents obtained cannabis from "a friend or someone they know", 35.9% from a compassion club, 30.8% from street dealers, and 8.5% grew their own cannabis without a license. Note that almost half the respondents reported that they obtain cannabis from more than one source.

The Government's Cannabis

The cannabis grown under contract for the government has received much media attention and has been subject to much criticism. Changes to the product continue to be made based on feedback received from the people who are using the product. The number of people ordering cannabis from the government remains low. Only 1.7% of the me-

dicinal users of cannabis we consulted reported that they obtain their supply from the government. Considering the current public attitude towards the government’s cannabis, the fact that the government only provides one strain of cannabis to authorized persons, and the government’s expressed intention to eventually phase out licenses to produce, we are concerned that people living with HIV/AIDS will have to continue to break the law to supply themselves with cannabis for their medicinal purposes, perhaps at an even greater proportion than is currently the case. We favour providing authorized persons with a variety of legal options and products. Offering only one legal source and only one strain of cannabis for distribution to authorized Canadians may not be a constitutionally adequate alternative to the diverse supply currently available to them through licenses to produce, unauthorized compassion clubs, or within the black market.

Licenses to Produce

Our consultation revealed that 8.5% of medicinal cannabis users had obtained a license to produce cannabis for medical purposes, and 4.3% had a designated producer. Health Canada has stated that its vision is to eventually phase out licenses to produce cannabis for medical purposes and to make the government’s cannabis available through Canadian pharmacies. While we support the development of pharmacy distribution of medical cannabis, we do not support eliminating legal options for authorized persons. We support a person’s choice as to how they wish to obtain cannabis for their medicinal needs, according to what best suits their individual needs.

For many, the decision to grow their own cannabis is purely economical, and they are likely to continue growing their own until other provisions are made to assist them with the costs. Producing their own cannabis also enables people to choose the strains that work for them and to control the conditions under which the cannabis is grown. Some people tell us that they will continue to produce cannabis for themselves regardless of whether or not they can obtain a license, which is also alarming. Seriously ill Canadians should not be forced to hide and ‘go underground’ to have access to the therapy of their choice. Moving toward further limiting legal options for se-

riously ill Canadians without financial compensation is a step backward in ensuring legal access to the treatment of their choice without fear of prosecution, and we question the constitutionality of doing so.

Community-Based Distribution of Cannabis

Eventually, Canada has to develop an adequate model for the distribution of legal, safe and affordable medical cannabis to ensure that seriously ill Canadians do not continue to rely on the black market as their source of cannabis. Based on our community action principles² of empowerment, community support, self-help, holistic approach, accountability, harm reduction and greater involvement of people living with HIV/AIDS, we favour a not-for-profit, community-based model of distribution of medicinal cannabis and of its related services. Some compassion clubs (medicinal cannabis dispensaries) in Canada meet these principles, and the more established clubs have developed guidelines for operational standards that all clubs can voluntarily adhere to. These organizations also offer a number of different strains and alternatives to smoking, and are currently serving more than 10,000 Canadians. Other models, such as community gardens run by and for people who use cannabis as therapy, could also be considered. We will continue to advocate for operational standards of compassion clubs, especially with regard to quality control of the cannabis they provide, and for their inclusion in a legal system of distribution of cannabis for medical purposes. We do not exclude other ways of distributing cannabis for medical purposes, for example through the pharmacy distribution model proposed by Health Canada. However, we believe in providing options to people to best suit their needs.

Informed Choice

The Canadian AIDS Society is driven by community action principles. People living with HIV/AIDS must be directly involved in the decisions that affect their lives and in the organizations that serve their needs. Canadians told Commissioner Romanow³ that they want to take charge of their health care. We need to provide them with the resources to make informed choices, and with safe and affordable products.

As with any activity that is forced underground, the prohibition on cannabis has resulted in a societal silence on the subject its use for medicinal purposes. People do not discuss the use of cannabis openly, except in closed circles, for fear of criminal prosecution. Prohibition has an impact on the everyday life of a person who uses cannabis for medicinal purposes. The silence that surrounds cannabis use results in a lack of information for people who use it for medicinal purposes.

The people we consulted expressed their need for information when it came to all aspects of the use of cannabis for medicinal purposes: scientific and medical evidence of the therapeutic effects of cannabis, how to access cannabis for medicinal purposes, the MMAR and the federal medical cannabis

"Many people are in a situation where they have to break the rules to be able to supply themselves."

—Focus group participant

program, alternatives to smoking, harm reduction strategies, and more.

We have answered some of this call for information by producing a series of fact sheets on Cannabis and HIV/AIDS, available on our web site at <www.cdnaids.ca/cannabis>.

Stigma and Discrimination

The use of cannabis is associated with stigma in Canadian society. Medicinal users of cannabis are often met with laughter, scepticism, or with negative reactions, all of which may have negative consequences on their everyday life. The federal medical cannabis program and the ID cards that are issued to authorized persons have helped to facilitate an acceptance of the medicinal use of cannabis. They have also brought some credibility and legitimacy to the use of cannabis for medical purposes and helped improve the image of cannabis use. These positive aspects of enabling legal access to cannabis for medical pur-

poses are slowly shifting Canadians' perceptions of medicinal cannabis use, which in turn contributes to the quality of life of the people who use it.

However, too many seriously ill Canadians remain marginalized for the medicinal use of cannabis. When people are forced into hiding for fear of stigmatization or criminal repercussions, the unspoken becomes a dark cloud over their lives. The fear-mongering that has taken place around cannabis use in this climate of prohibition has also fed the beast. Breaking this silence and encouraging dialogue can be challenging, and can go a long way to lifting the smoke screen.

During our consultations, people described instances when they felt discriminated against for their medicinal use of cannabis both by their peers who do not use cannabis for medicinal purposes and by the medical system in general. Denying a seriously ill person access to health care services is not only unethical, it also violates the very essence of our universal health care system. In some cases, people can be legally protected from certain forms of discrimination.

The Canadian AIDS Society is committed to disseminating information about the use of cannabis for medicinal purposes, to bringing forward the voices of people living with HIV/AIDS and the realities they face when they choose cannabis as part of their therapy, and to encouraging dialogue on these important public health issues. We invite all of the key stakeholders, including the government, to join our efforts.

Conclusion and Recommendations

The *Marihuana Medical Access Regulations* are a work in progress and there are still many challenges to address within the federal medical cannabis program. It must be remembered that the creation and amendment of the MMAR and the federal medical cannabis program was imposed on Health Canada by the courts, and it may be challenging to secure necessary reform of the MMAR without the fear of litigation. Litigation is a very crude instrument for the formulation of public policy. Nego-

tiation and discussion with the government may be a more effective vehicle for proposed reforms to the MMAR. The Canadian AIDS Society remains committed to participating in consultations with the government and other key stakeholders. Based on our ongoing consultations with people living with HIV/AIDS, we will continue to work with Health Canada and provide input into the federal medical cannabis program so that it may better meet the needs of seriously ill Canadians. We propose the following recommendations. For more details, please consult the full report.

Summary of Recommendations

1. Need for Evaluation and Accountability of Federal Medical Cannabis Program

We, the Canadian AIDS Society, recommend that the Auditor General conduct a performance audit of all aspects of the current federal medical cannabis program to ensure that resources are adequately allocated to address the needs of seriously ill Canadians.

2. Need to Be Included in the Policy Dialogue

We recommend that the government re-establish a Stakeholder Advisory Committee on Medical Cannabis to provide a forum for key stakeholders to exchange information and provide ongoing input into the federal medical cannabis program and the policies, regulations and legislation that govern it.

3. Need to Be Protected from Criminal Prosecution

Lack of Awareness about the Federal Medical Cannabis Program

We recommend that Health Canada and organizations such as the Multiple Sclerosis Society, the Arthritis Society, the Canadian Cancer Society and others disseminate accurate and up-to-date information about the federal medical cannabis program and the *Marihuana Medical Access Regulations* to

the people they serve, and that they build the capacity of their member organizations, if this applies, to respond to information requests and to assist them with the application process. We are open to collaborating on these efforts, within the confines of available resources.

Federal Medical Cannabis Program's Application and Renewal Process

We recommend that Health Canada evaluate its resource needs and establish mechanisms to ensure that applications and renewals are processed in a timely manner to avoid gaps in a person's legal authority to possess and produce cannabis.

Reluctance of Physicians to Participate in the Program

We recommend that researchers conduct a survey of physicians to obtain information about their attitudes toward the use of cannabis for medical purposes, as well as to assess their knowledge of the medical applications of cannabis in the treatment and symptom management of HIV/AIDS. Once this information is available, a continuing education module can be developed to provide proper training to physicians about the use of cannabis for medical purposes.

If they have not already done so, we recommend that the Canadian Medical Association and other medical associations communicate the changes made to the MMAR to their member physicians to ensure that they have the latest information.

If they have not already done so, we recommend that the Canadian Medical Protective Association communicate with their member physicians to inform them of the Release Form for Medical Practitioners and its purpose with regard to liability.

4. Need to Address Stigma and Discrimination

We recommend that all of the key stakeholders, including the government, join our efforts in disseminating information about the medicinal use of cannabis and the federal medical cannabis program. We must also find opportunities to engage others in

a dialogue about the use of cannabis for medicinal purposes, in an effort to reduce the stigma associated with the medicinal use of cannabis.

We call on all levels of government and on the medical and scientific communities to take measures to ensure that there is adequate research, information dissemination, and related services so that seriously ill Canadians are provided with standards of care around their treatment of choice, without discrimination.

5. Need to Generate and Disseminate Information Regarding the Medicinal Use of Cannabis

We call on our member organizations to assist us in disseminating the fact sheets on Cannabis and HIV/AIDS, to develop position statements on the use of cannabis as therapy for people living with HIV/AIDS, and to support our advocacy efforts with regard to the use of cannabis for medicinal purposes by people living with HIV/AIDS.

We recommend that all key stakeholders, including Health Canada, engage in the gathering and dissemination of information regarding the use of cannabis for medicinal purposes to people living with HIV/AIDS and other seriously ill Canadians.

We recommend that the Canadian Institutes for Health Research, through the Medical Marijuana Research Program, issue a Request for Proposals for a Marijuana Open Label Safety Initiative for a trial to assess the safety and efficacy of smoked cannabis on appetite stimulation, nausea and vomiting, pain, and other HIV/AIDS related symptoms. If researcher interest is still low or non-existent, we recommend that Health Canada actively solicit research in this area through targeted contracts.

6. Need to Access to Legal, Safe, Reliable and Affordable Sources of Cannabis

Access to Testing

We recommend that Health Canada, under the Controlled Drugs and Substances Act, license Canadian

laboratories to test medicinal cannabis that is grown by persons who hold an Authorization to Possess and/or a License to Produce through the MMAR.

The Government's Cannabis

Given the low uptake of the government's cannabis by authorized persons, we recommend that Health Canada provide 5g samples of cannabis to newly authorized persons to encourage more authorized persons to try the government's product and subsequently order it, to minimize the number of authorized persons that depend on an illegal source of cannabis.

Licenses to Produce

We strongly oppose the government's vision to phase out Personal Licenses to Produce. We suggest that the government review the distribution of cannabis for medical purposes overall and evaluate how it can best suit the needs of authorized persons.

We recommend that Health Canada lift restrictions imposed on designated producers and allow them to grow for multiple authorized persons, and collectively with more than two other designated producers. The cannabis production facilities could be regulated and monitored to ensure quality control.

Community Based Distribution of Cannabis

We recommend that the government authorize compassion clubs that meet defined operational standards and recognize them as legal dispensaries of medicinal cannabis.

Reimbursement for Medical Cannabis

We call on the government and the medical and scientific communities to take the necessary steps to facilitate the process of obtaining drug approval, or conditional drug approval, for cannabis so that physicians can prescribe it and consideration can be given to having the costs of the product covered under provincial drug plans. Until such a time, consideration must be given to other mechanisms for reimbursement of the costs of medical cannabis for seriously ill Canadians.

We recommend that the Minister of Finance revise the medical expense tax credit to allow authorized persons who have a license to produce cannabis for medical purposes to claim expenses incurred in producing cannabis for their medical purposes.

Concluding Remarks

Seriously ill people have a constitutional right to use cannabis as part of their therapy. This right is established and will remain as long as the prohibition on cannabis is upheld. Securing this right through the federal medical cannabis program is but one step. We must work together to ensure that this right is recognized and upheld and to facilitate access to the federal medical cannabis program by both addressing the existing barriers, and ensuring that seriously ill Canadians are protected from criminal prosecution for using the therapy of their choice. We must work collectively to find creative solutions in providing safe, legal and affordable sources of cannabis for seriously ill Canadians, and to end the reliance on the black market. We must also address the information needs regarding the use of cannabis as a therapy to ensure that people can make informed choices about their health and well-being.

We hope that providing the voice of people living with HIV/AIDS and sharing the daily realities of obtaining legal access to cannabis for medicinal purposes will contribute to a better understanding of the current federal program, and to the consideration of policies that are better suited to address the needs of end users. This is our call to action to all key stakeholders. Priority must be placed on the needs of seriously ill Canadians.

1 Canadian AIDS Society. Cannabis as Therapy for People Living with HIV/AIDS: “Our Right, Our Choice.” Full report available from <www.cdnaids.ca/cannabis>.

2 Canadian AIDS Society. The Community Action Principles of the Canadian AIDS Society. Adopted by the CAS Board of Directors, May 1991. Amended December 2005. Available at <www.cdnaids.ca/web/casmisc.nsf/cl/cas-gen-0051>.

3 Romanow, Roy J. Commission on the Future of Health Care in Canada. Building on Values: The Future of Health Care in Canada. Final Report, November 2002.

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