

20 March 2018

Submission on the Misuse of Drugs (Medicinal Cannabis) Amendment Bill

From: The Motor Neurone Disease Association of New Zealand

Motor neurone disease (MND) is a terminal neurological condition that causes rapidly increasing disability and loss of independence. It frequently strikes healthy people in middle age.

The Motor Neurone Disease Association of New Zealand (MND New Zealand) supports people with motor neurone disease (MND) in New Zealand. We also support their families, carers and health professionals.

MND New Zealand does not have a view either in favour or against the Misuse of Drugs (Medicinal Cannabis) Amendment Bill. We have encouraged members of our community to make their own personal submissions to this Select Committee.

In preparing this submission, we surveyed our support staff who every day connect with people with MND, their families and health professionals.

We also commissioned a report, together with Multiple Sclerosis New Zealand: 'Review of Current Research Regarding the use of Medicinal Cannabis for MS and MND Symptom Management' (attached to this submission; also available online at <https://mnd.org.nz/wp-content/uploads/2018/02/Medicinal-Cannabis-Research-Report-December-2017-MSNZ-and-MND.pdf>).

We wish to make the following general comments:

Equal rights for people with MND

Our primary purpose in making this submission is to ensure that any rights that may be created by the Bill do not discriminate against people with MND.

MND destroys the nerve cells that control our muscles. This eventually leaves the majority of people with MND unable to move their limbs or fingers, unable to walk, drive, hold, eat or communicate verbally. Many people with MND greatly lose their independence and rely on carers to help them in most of their daily tasks.

If people with MND use cannabis for relief from the symptoms of MND, many are therefore reliant on a carer to procure and prepare their cannabis, as they are physically unable to do so themselves.

In its current wording, the Bill does not protect carers of people with MND who procure, prepare or temporarily possess cannabis (or a cannabis tool) on behalf of a person with terminal illness.

We believe this discriminates against those people with MND who are physically unable to procure or prepare cannabis.

Information about cannabis use for MND

Our secondary purpose is to share information about the use of cannabis to treat symptoms of MND, a terminal disease, which may inform your consideration of the proposed amended Bill.

In February we surveyed the six staff of our support service. Together they support people with MND in every part of New Zealand, and their families, carers and health professionals. There are 100+ people in New Zealand who are newly diagnosed with MND every year.

Of six responses, three MND support staff said they currently had clients who are using illicit cannabis to manage the symptoms of their MND. These clients self-reported benefits including: relief from anxiety, relieved pain, reduced tremors, relief from shortness of breath. There was one reported negative effect: increased imbalance.

Five out of six MND support staff indicated they currently felt comfortable discussing illicit cannabis use with their clients. Two out of six said that if cannabis was legal for people with MND, they would feel more comfortable discussing the potential risks, benefits and appropriate forms of ingestion for people with swallowing or respiratory difficulties.

One said: "I would feel more comfortable if clients were using prescribed medicinal cannabis in regards to their personal medical safety."

Our report, 'Review of Current Research Regarding the use of Medicinal Cannabis for MS and MND Symptom Management' (attached to this submission; also available online at <https://mnd.org.nz/wp-content/uploads/2018/02/Medicinal-Cannabis-Research-Report-December-2017-MSNZ-and-MND.pdf>), examines in more detail the risk/benefits of using medicinal cannabis, and reviews the current international recommendations for the safe use of medicinal cannabis for MS and MND symptom management.

The report finds benefit in using cannabis for the treatment of several symptoms of MND: pain, spasticity, weight loss, and potential to slow disease progression.

It also finds some risks: dependence, impairment due to Δ THC intoxication, potential worsening of MND-related cognitive impairment, potential risk of mental illness, smoke inhalation, and potential contaminants.

Our report suggests the following risk management strategies:

- Limit access to only those 18 and over
- Regulate the proportion of Δ THC acceptable in cannabis plants for medicinal use ^[1]_[SEP]
- Ensure that driving under the influence of cannabis remains illegal ^[1]_[SEP]
- Ensure that medicinal cannabis use is contraindicated in people with a history of schizophrenia and psychosis
- Recommend cannabis be vaped, ingested, or used in a tincture, rather than smoked
- Establish regulations which ensure medicinal cannabis is grown in contaminant free conditions

Finally, we also refer you to 'Cannabis and its Use in Symptom Management of ALS/MND', a presentation from the International Symposium on MND/ALS in December 2017 (view the presentation here: <https://www.youtube.com/watch?v=ypkG2IRaXSU>).

The presenting researchers found that in the US, where MND is known as ALS (amyotrophic lateral sclerosis), 30% of people with ALS/MND use cannabis to manage their symptoms. Of this 30%:

- Reported benefits included: pain relief, decrease in muscle cramping, decrease in muscle spasms, decreased anxiety, improved sleep, reduced weight loss due to improved appetite.
- The benefits of medical strains of cannabis were believed superior than 'off the street' or home-grown cannabis.
- 57% believe using cannabis has positively impacted their ability to complete daily tasks.
- 69% believe using cannabis has positively affected their ability to cope with the progression of their ALS.
- 91% believe using cannabis has increased their quality of life.
- One-third used cannabis high in Δ THC, one-third used CBD, and one-third did not know what type they used.

Funding for further research

The tertiary purpose of our submission is to advocate for government funding of ongoing research into the use of cannabis to treat the symptoms of MND and other neuromuscular and neurodegenerative diseases.

MND New Zealand believes it is important that further, well-designed scientific studies are conducted to investigate the effects, benefits and risks of cannabis on people living with MND.

We need more information so we can empower patients to make informed decisions about their care, and educate patients about the types of cannabis available and the recommended ways to administer it for people with MND.

We wish to make the following specific comments about the Misuse of Drugs (Medicinal Cannabis) Amendment Bill:

Clause 4 – Section 2 amended (Interpretation)

This defines 'terminal illness' as an illness from which a person can reasonably be expected to die within 12 months. About 80% of people with MND die within 5 years of their diagnosis. They are terminally ill for all of this time, and suffer symptoms that our research indicates may potentially be relieved by cannabis for all of those years (pain, muscle cramping, muscle spasms, anxiety, difficulty sleeping, weight loss). Some of these symptoms (anxiety, difficulty sleeping, muscle spasms) may peak early in the disease progression. We believe limiting the definition of 'terminal illness' to those expected to die within 12 months discriminates against people who have been recently diagnosed with MND, an incurable terminal neurodegenerative disease, who may reasonably expect to live a further two to five years.

Clause 5 – Section 7 amended (Possession and use of controlled drugs)

(2A) does not protect carers of people with MND who procure, prepare or temporarily possess cannabis on behalf of a person with MND who is very limited in their mobility and unable to complete these actions unaided. We believe this discriminates against those people with MND who are physically unable to procure or prepare cannabis.

Clause 6 – Section 13 amended (Miscellaneous offences)

(1A) does not protect carers of people with MND who procure, prepare or temporarily possess a cannabis tool on behalf of a person with MND who is very limited in their mobility and unable to complete these actions unaided. We believe this discriminates against those people with MND who are physically unable to procure or prepare cannabis.

Recommendations:

1. We recommend that the Bill consider and ensure it is inclusive of people with MND who have very limited mobility, and who are unable to procure or prepare cannabis unaided.
2. We recommend that Government provides funding for ongoing research into the use of cannabis to treat the symptoms of MND and other neuromuscular and neurodegenerative diseases.
3. We recommend that the Bill defines “terminally ill” as an illness from which a person can reasonably be expected to die (with no time frame specified).
4. We recommend that the Bill provides protection for carers who procure, possess or prepare cannabis on behalf of a terminally ill person.
5. We recommend that the Bill provides protection for carers who procure or possess a cannabis tool on behalf of a terminally ill person.

We also repeat the risk management recommendations published in our report, ‘Review of Current Research Regarding the use of Medicinal Cannabis for MS and MND Symptom Management’:

1. Limit access to only those 18 and over.
2. Regulate the proportion of Δ THC acceptable in cannabis plants for medicinal use. ^[1]_{SEP}
3. Ensure that driving under the influence of cannabis remains illegal. ^[1]_{SEP}
4. Ensure that medicinal cannabis use is contraindicated in people with a history of schizophrenia and psychosis.
5. Recommend cannabis be vaped, ingested, or used in a tincture, rather than smoked.
6. Establish regulations which ensure medicinal cannabis is grown in contaminant free conditions.

Thank you for your consideration,

Beth Watson

President, The Motor Neurone Disease Association of New Zealand

On behalf of The Motor Neurone Disease Association of New Zealand