



# BELGIAN CHARCOT FOUNDATION

## FIGHTING MULTIPLE SCLEROSIS

Number 46  
November 2019

# NEWSLETTER

Belgian Charcot Foundation  
Public interest foundation

Under the Patronage of Her  
Majesty The Queen

Huart Hamoir Avenue 48  
B - 1030 Brussels  
Phone: +32 2 426 49 30  
Fax: +32 2 426 00 70  
info@fondation-charcot.org  
NN 468 831 484

Photo Credit: iStock & Shutterstock  
Responsible publisher: I.Bloem  
Av. Huart Hamoir, 48 - 1030 Brussels  
© Belgian Charcot Foundation 2019



[www.fondation-charcot.org](http://www.fondation-charcot.org)  
BE34 6760 9000 9090

## Young people and MS

This new issue of the Charcot Foundation Newsletter focuses on young patients who develop multiple sclerosis before the age of 30, and also on the use of cannabis and its derivatives in the (mainly symptomatic) treatment of the disease. These are two very real issues which are frequently encountered by clinical neurologists.

The development of MS in young people who have not yet completed their studies or are starting out in their careers comes as an emotional shock and a severe challenge. Acceptance of the disease, of the presence in one's body of an as-yet-incurable condition, of a treatment which can be arduous and is administered over the long term are as many obstacles to the fulfilment of the life plans each of these young patients had made for themselves prior to their diagnosis. For most of them, the date on which they were informed of their condition remains an indelible memory. The article by Christa Expeel and Bernard Dachy provides a comprehensive and clear-sighted summary of the problems of treating young patients, and in particular concerning the importance of respecting the patient's wishes and the need for the personal and emotional support required for the patient to gradually accept the disease and its treatment.

These young patients and older ones alike frequently hope that cannabis derivatives will supply a miracle cure. Miguel D'haeseleer describes the potential contribution of tetrahydrocannabinol (THC) and cannabidiol (CBD) to the symptomatic treatment of MS as well as – possibly – its immunomodulatory therapy. It has to be admitted that many data still remain unknown to us and that further in-depth research is required not only on the beneficial effects but also on the potential serious side-effects of these substances. At this point in time, the precautionary principle needs to remain in force and this treatment must be limited to patients in whom spasticity and pain are resistant to the usual drug treatments.

Clearly, then, our job is to preserve the future of these young patients and neurologists are, so to speak, the guardians and custodians of their brains. Progress therefore absolutely needs to be made not only in bringing about of remissions, but also in repairing of installed lesions and, ultimately, towards a cure for MS – that is, for its immunological mechanisms as well as for its most invalidating symptoms.

Prof. Dr. **Christian Sindic**  
President



Follow us on Facebook

# DIAGNOSIS & TREATMENT

## Young people and MS

Multiple sclerosis is the commonest neurological disease affecting young adults. In patients under 30, treatment needs to be adjusted accordingly. Neurologist Dr Dachy and MS nurse Christa Expeel share their experience.

Three years ago, at CHU Brugmann, we developed a multidisciplinary department for patients with multiple sclerosis (MS) and related neuroimmunological diseases. A neurologist specialised in MS, a resource nurse, two physiotherapists, a social worker and a psychologist endeavour to optimise overall care for the patient by designing an appropriate and customised care pathway. Looking back, we realised that patients aged 18-30 often differ from older patients in their attitudes and behaviours towards their MS, its treatment and monitoring.

Almost all of them are treated with oral disease-modifying first-line treatments, and in some cases, when the disease is highly active or even aggressive, with second-line treatments from the very beginning. They are often of immigrant origin and the second or even the third generation born in Belgium.

### The ordeal of diagnosis

It would appear that diagnosis and its notification to young patients have characteristics of their own.

Young people are very keen to know the cause of their symptoms and want them to go away as soon as possible. Some of them immediately mention MS as they have officially been supplied with this information in the course of an external consultation or it has been suggested by their family and friends, internet searches or discussion forums.

The length of time required for diagnosis may appear interminable. For instance, they find it difficult to accept the requisite criterion of dissemination over time, even though the renewed use of lumbar puncture may sometimes resolve this issue. However, lumbar punctures can be a difficult experience for young people as this is often the first time they are hospitalised, and they are likelier to suffer post-lumbarpuncture syndrome.

The actual notification of the diagnosis may induce a variety of reactions. Some do not react immediately and a language barrier may lead to misunderstanding of the information supplied. They may panic, become unable to think, not accept reality and reject it. It is too much to bear for them to learn that they have a chronic disease, that they will not get better and that they will have to undergo long-term treatment; they are frightened and fear ending up in a wheelchair. They do not understand why this

is happening to them and cannot accept that they are going to have to live with the disease.

We also offer psychological support, even though they do not always find the prospect attractive.

### Choice of treatment

The choice of treatment is a crucial stage which may last some time despite the fact that it cannot be delayed forever. Young patients want a quick fix, a "magic" treatment that is easy to take. They need to understand that although a disease-modifying treatment is a guarantee for the future it will not cause residual symptoms or any existing disabilities to go away.

This is also the time when the importance of good lifestyle and eating habits have to be emphasised: of practising a sport or exercising under the supervision of a physiotherapist, or reducing and preferably giving up the consumption of tobacco, cannabis or alcohol.

We encourage them to rely on a trusted adult, a family member or person from their immediate circle, to provide the necessary support. Quite frequently, we also need to deal with the parents' anxiety even more than with the patient's actual suffering, taking into account their level of education, cultural practices and the language barriers which may constitute an obstacle to the "rational" approach to the disease as we conceive of it. Some young patients prefer to come alone as they do not wish their family or friends to know and are ashamed of being ill. They are anxious not to worry their parents, who in their opinion would not understand the situation. As for more personal issues such as planning a pregnancy or the formation of an intimate relationship, they may require one-on-one consultations.

Our working principle is to set appointments (check-ups, examinations, imaging, etc.) in agreement with the patients and according to their availability.

### Shared responsibility

Once they are feeling better, young patients want to suspend their treatment. Holidays often play a part in this, sometimes



**FOLLOW US ON INSTAGRAM:**  
**@FONDATIONCHARCOTSTICHTING**



due to the atmosphere of insouciance they generate or because the patients wish to hide from their families that they are taking medication and are ill. In the event of a relapse, they tend to impulsively go to the emergency department, which may lead to hospitalisation in an atmosphere of anxiety or panic.

It is important to be aware that young patients can be unpredictable: we need to spend more time with them and make ourselves more available to them, to ultimately ensure that we see them less often – or are able to deal with emergencies such as "I've lost the bag I keep my drugs in" or "I've lost the prescriptions". We need to encourage them to keep up their studies, issue medical certificates wisely, understand the patients' situation without enabling them to use their disease as an excuse for dropping out, and generally act the part of a referee.

**“** *It is up to us to be there at such times, without taking over for them, but in order to help them become full partners managing their disease.*

When healthcare staff adapt their approach to the requirements of young patients, the result is frequently a genuine, reliable and trusting relationship. After all, MS forces young people to mature earlier and adapt, compromise and negotiate with themselves and other people the way adults do, in the awareness that the road they initially planned to take will have its obstacles and pitfalls. It is up to us to be there at such times, without taking over for them, but in order to help them become full partners managing of their disease.

**Christa Expeel**  
MS Nurse

**Dr Bernard Dachy**  
Head of Neurology Department  
CHU Brugmann, Brussels





**WHAT IF YOU WERE THE ONE  
WHO FOUND THE ANSWER?**

**A BEQUEST CAN MAKE  
ALL THE DIFFERENCE.  
THINK ABOUT IT.**



**€7 A MONTH FOR ONE YEAR  
= ONE DAY OF RESEARCH**



Donating €7 a month by standing order really supports research into MS in Belgium.

**BE34 6760 9000 9090**

Gift of €40 or more are tax deductible.



[www.fondation-charcot.org](http://www.fondation-charcot.org)

► *The Belgian Charcot Foundation complies with privacy legislation.  
You will find more information on how we manage personal data  
on: [www.fondation-charcot.org](http://www.fondation-charcot.org)*

**"I would like to help overcome Multiple Sclerosis and I would like to make a gift in my will or living trust to the Belgian Charcot Foundation"**

I would like to receive free documentation  
 I would like to be contacted without any obligation  
 My (mobile) phone number: .....

My personal details  Mrs.  Mr.

First name: .....

Name: .....

Street: .....

Number: ..... Box: ..... Postcode: .....

City: .....

E-mail (optional): .....



**Please send this reply form in a stamped envelope to:**  
**Belgian Charcot Foundation**  
**Mrs Isabelle Bloem**  
**48 Avenue Huart Hamoir**  
**1030 Brussels - Belgium**  
**or by e-mail to :**  
**[isabelle.bloem@fondation-charcot.org](mailto:isabelle.bloem@fondation-charcot.org)**

The Belgian Charcot Foundation respects the law on the protection of your personal data. The information collected through this form will only be used to answer your request for information about gifts and wills. More information in our privacy statement at [www.fondation-charcot.org](http://www.fondation-charcot.org)



# RESEARCH

## Cannabis in the treatment of MS

Multiple sclerosis is a chronic inflammatory disease of the central nervous system that affects over two million people worldwide. Patients may suffer from a wide range of disabling complaints which are not always easy to treat. Although cannabis is best known as a psychoactive recreational drug, it is also increasingly associated with a variety of positive medical effects.

A survey of MS patients had recently revealed that almost half of them have already considered using cannabis in one form or other to minimise their symptoms, and approximately one quarter of them have already done so. The media are now taking a great deal of interest in the subject, generating a risk of controversy, uncertainty and unrealistic expectations in the process. The purpose of this article is to supply reliable information concerning the medical use of cannabis in cases of MS, with emphasis on potential positive effects, without, however, ignoring the potential hazards and legal aspects.



### Biological background

Cannabis has been produced for a very long time from various plants (e.g. *Cannabis sativa*) which originate in Central and South Asia and may contain as many as one hundred different cannabinoids. These are chemicals which affect certain receptors in the human body. The first type of cannabinoid receptor (CB1) is mainly found in our nervous system. Binding of these cannabinoids to these receptors can alter neurotransmission (i.e. communication between nerve cells) and affects pain control, memory and locomotion. This is the main source of the medical effects of cannabis. The second type of receptor (CB2) mainly controls the functioning of the immune system. The cannabinoids most present in cannabis are tetrahydrocannabinol (THC) and cannabidiol (CBD). In general, the plants contain more of the former. THC has a far more powerful impact than CBD on the CB1 receptors, and for this reason is considered to be responsible for most of the potential therapeutic and psychoactive effects. It is not exactly known how

CBD works, but other paths are probably involved. CBD itself is not psychoactive and may even counterbalance the psychoactive effects of THC. Not only are cannabinoids produced by plants, the human body itself generates some and they can even be manufactured synthetically.

### Medical effects

Currently, Sativex® is the only authorised cannabinoid-based drug in Belgium. It is a solution of fixed quantities of THC and CBD and designed to be sprayed on the lining of the mouth. Scientific research has shown that Sativex® and medicinal cannabis in general can have positive effects on the subjective interpretation of spasticity in MS patients, and probably also on pain, sleep quality and bladder control. In Belgium, the drug is only reimbursed by social security in the case of MS patients who experience disruptive levels of spasticity which have not responded adequately to traditional spasmolytic medication (e.g. baclofen). But first, the patient's symptoms must satisfactorily improve during a trial period of 8 to no more than 12 weeks. The system is strictly controlled as detailed clinical information must be kept and the medication may only be supplied at set intervals by a hospital pharmacy. As yet, there are no direct comparative studies between cannabinoids and traditional spasmolytic drugs. As the CB2 receptors are involved in the immune system, there is also a theoretical possibility that cannabinoids may actually affect the progress of MS. Although so far research in this direction has proved disappointing, additional studies are probably required. In some countries, medicinal cannabis can be used in cases of epilepsy, nausea and vomiting.

**“ Additional research on medicinal cannabis should be encouraged**

### Side-effects

Although the medical use of cannabis can have side-effects, these are usually mild. Dizziness, concentration problems, dry mouth, nausea and increased fatigue are the most commonly



reported complaints. Exposure to cannabis has also been linked to the development of psychosis. For this reason, Sativex® may not be prescribed to patients with a personal or family history of psychosis, or if they suffer from a serious mental illness. A number of studies show that suicide risk is a potential concern, but so far this has not been adequately proven. The same applies to cardiovascular complications. However, the chronic use of cannabis does appear to have adverse effects on cognition. In the case of Sativex®, these are probably reversible, but long-term effects are as yet unclear. However, the likelihood of habit-formation and dependency is limited.

## The legal position

At this point in time, decriminalisation of the use of cannabis in general is very much in the air internationally. In Belgium, as in many other countries, the possession of small quantities exclusively intended for personal use is tolerated, despite being strictly prohibited by law. CBD-based preparations constitute an exception, provided the THC content is less than 0.2% and they are not intended for human consumption. This ensures that such products must be sold (officially) as massage oils, fragrances and the like.

On the other hand, the use of medicinal cannabis has been authorised in many countries. In this respect, Belgium remained somewhat lagging, until Sativex® under the conditions specified in the previous paragraph – became the only substance authorised by law. However, the Belgian Federal Agency for Medicines and Health Products issued a circular in August 2019 which interprets the law in such a fashion that chemists may use CBD as an ingredient in medically prescribed pharmaceutical compounds, provided the patient's (unavoidable) daily exposure to THC contamination does not exceed a specified limit. The consumption of CBD preparations procured through other channels is inadvisable as mistakes can be made in the exact composition. Belgian patients in possession of cannabis who travel abroad should also be aware that legislation may vary widely from one country to the next and in some cases may be applied very strictly. Finally, it should be pointed out that there are implications for drivers.

Whatever the circumstances, it is a punishable offence to drive if

the presence of THC in the body can be proven. In the event of a police check, drivers may be required to take a saliva test which can detect the presence of THC until approximately 14 hours after use.

## Conclusion

Although human beings have been using cannabis for centuries, its use for medicinal purposes is still in its infancy. This is partly due to legal restrictions, which are now currently being eased worldwide. Scientifically, the best demonstrated advantage of cannabis is the reduction of spasticity and pain in MS patients. In Belgium, Sativex®, a mixture of THC and CBD, is the only legally authorised drug and is dispensed under extremely strict conditions. As side-effects may occur, the main focus should always be on the overall improvement in the patient's condition. The legal requirements concerning fitness to drive constitute yet another legal hindrance. Additional research on medicinal cannabis should be encouraged, including on potential long-term effects (e.g. cognition) and the effects of CBD monotherapy. The presence of the CB2 receptor in our immune system also raises interesting questions about the ability of cannabis to play a more fundamental part in influencing the course of the disease via this pathway.

**Prof. Dr Miguel D'haeseleer**  
Neurologist, National Multiple  
Sclerosis Centre, Melsbroek  
and UZ Brussel, VUB

► *The references of all the studies mentioned are available on request to the Belgian Charcot Foundation.*

With the support of

 **Degroof  
Petercam**