

## Low Dose Naltrexone



Multiple sclerosis information

# Welcome to this Choices booklet about Low Dose Naltrexone...

MS-UK believes we must listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

**Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis**

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# What is Low Dose Naltrexone?

Naltrexone is a drug developed initially to treat addiction to opiate-based drugs, such as heroin or morphine. It belongs to a class of medications called opiate antagonists and offers no opioid or narcotic effect (1).

Low Dose Naltrexone (LDN) is simply naltrexone administered in small doses.

The low dose method of taking naltrexone was devised and developed in the mid-1980s by the late Dr Bernard Bihari in the United States, who initially used it to treat patients affected by human immunodeficiency virus (HIV).

**I have definitely had massive benefits taking LDN, it has worked really well for me**

The therapeutic use of LDN has grown rapidly since then, as an 'off label' treatment for the symptoms of many conditions including MS (2). The term 'off-label' means that the person prescribing the medicine wishes to use it in a different way than that stated in its licence (3).

## How naltrexone works

Fundamentally, naltrexone inhibits endorphins, which are hormones that the body produces naturally. Endorphins are the body's natural painkiller, plus they help to create a sense of wellbeing. It is believed that by inhibiting endorphins, the body reacts by producing more. The increase in endorphins helps to reduce the impact of pain and fosters a sense of wellbeing.

As mentioned, LDN is naltrexone delivered in a small dose, therefore it only inhibits endorphin production for a few hours before the body starts producing them naturally again, but at an elevated level. This is known as the rebound effect and only occurs due to the low dosage. The elevated level of endorphins produced can now act in synergy with the body's endorphin receptors, assisting in the regulation of cell growth and immunity (4). The rebound effect kickstarts LDN's therapeutic benefits, which are analgesic and anti-inflammatory in nature (5).

## Research into LDN

There is a fair amount of research that has looked into the benefits of using LDN as a therapeutic option for treating many different conditions and symptoms. That said, many studies and trials are small-scale, meaning further research is usually required to underpin the initial findings. Furthermore, MS-focused research is limited.

Below we will take a look at a selection of studies which may be of interest to the MS community.

## MS focused research

Most studies which have looked at how LDN may benefit people affected by MS have shown that it is generally well tolerated, may help with managing associated symptoms such as spasticity, pain fatigue and depression, and improve overall quality of life.

In 2008 a six-month phase II pilot trial of 40 people with primary progressive MS (PPMS) was primarily looking at the safety and tolerability of LDN within the group's participants. The study reported that it was generally safe to use and well-tolerated, however, some participants reported an improvement in symptoms such as pain and fatigue, but most significantly a reduction in levels of spasticity (6).



**I have taken LDN in the past but I found that it didn't make any difference to me**



Interestingly, in 2010, two separate small-scale studies that were looking for evidence as to how LDN could be used therapeutically for people with MS provided contrasting conclusions in terms of its effect on quality of life.

A 17-week long randomised trial involving 96 participants with relapsing remitting (RRMS) and secondary progressive (SPMS) MS was conducted, with the objective being to determine if LDN could improve quality of life in both a physical and mental sense. In this trial some participants were given LDN, while the rest were provided with a placebo. The study concluded that while LDN was deemed as a relatively safe therapeutic option, neither group showed any meaningful difference in overall quality of life scores (7).

**I have been taking LDN since 2004 and feel certain it has improved most symptoms, and I feel it has slowed down progression**

The same year another small-scale study took place involving 80 participants, all of whom had received an MS diagnosis. The aim was again to determine if LDN can have a positive impact on the quality of life in people with MS. Participants were given either a 4.5mg dose of LDN or a placebo, over an eight-week period. This study found that the participants who were assigned to the LDN group reported significant improvement on a mental health quality of life measure (8).

What these studies did have in common was the conclusion that LDN was generally well tolerated, and that more research

into the efficacy of LDN treatment in improving overall quality of life for people with MS was needed.



**My MS improved a lot after taking LDN**



### **Other research of interest**

As mentioned previously, there have been many studies, trials and reviews that have looked at the use of LDN for managing a variety of conditions and associated symptoms. Perhaps of most interest to the MS community are those which have focused on the safety and efficacy of LDN in managing chronic pain, particularly that of a neuropathic nature.

Later, in the further information section of this booklet, we signpost to the organisations LDN Research Trust and LDNscience whose websites provide information and links to a catalogue of trials, studies and scientific reviews. However, one particular and very recent study which was concerned with the safety and efficacy of LDN treatment for managing chronic pain may be of interest to the MS community.



Whilst conducting research prior to undertaking their study, the authors found that previous studies had evidenced how LDN can be effective in the management of chronic inflammatory and neuropathic pain. The study itself focused on 115 patients from a clinic in the United States, all of whom had been prescribed LDN as a means of pain management between 2009 and 2022. The study reported that two-thirds of patients found LDN was effective in helping them to manage the impact of pain, with the authors concluding that LDN may offer meaningful relief for patients affected by refractory chronic pain (9).

Additionally, in 2019 the authors of a review which examined the outcomes from 89 randomised controlled trials of naltrexone use of variable doses, involving 11,184 participants, concluded that naltrexone is safe to use in the short to medium term (10). However, more research is required to underpin its long-term safety.

## Accessing LDN in the United Kingdom

Naltrexone is licenced by the National Institute of Health and Care Excellence (NICE) to manage opiate dependency in the UK (11). However, LDN has not been licensed for the treatment of MS symptoms and is not widely recommended for use to treat people with MS within the NHS. As previously mentioned, the use of LDN to manage MS symptoms is sometimes described as 'off-label', which is a term used for medications that are used to treat conditions other than those for which they are approved (12).



**I have to pay privately. My GP was told she wasn't allowed to prescribe it**



Many GP's and neurologists are naturally cautious, given the guidelines within the NHS, about prescribing LDN as an 'off-label' treatment for MS symptoms. For some this caution can be because of their unfamiliarity with LDN. The LDN Research Trust have published a useful factsheet (13) and guide for prescribers (14) that may be helpful. If you are considering trying LDN, these packs contain useful information for your GP or prescribing clinician. By obtaining a prescription for LDN from your GP, you will be able to get it dispensed at the standard prescription rate. As LDN is unlicensed, your GP may refuse to prescribe it and you may need to obtain a prescription privately.

If you are unable to obtain an NHS prescription from your GP, they may be willing to write you a private prescription but will most likely charge for this. You could also get in touch with a private specialist practice or an online GP service. It is likely that you will be asked to provide them with a letter from your GP or neurologist confirming that you have MS, a summary of your medical history, including any other conditions you live with, and any existing medication you take. If you have a private prescription, you can obtain LDN from a specialist pharmacy.



**‘I wish that doctors were more proactive, as I felt I had to do a lot of my own research into LDN, then I had the battle of getting it’**



**I have a repeat prescription for LDN from a brilliant NHS doctor who had to fight to allow me to have it. She has taken full responsibility for prescribing it to me**



The LDN Research Trust’s website provides a database of LDN prescribers and dispensing pharmacies around the world, including the UK.

It is important to note that LDN obtained from sources other than a prescribing chemist cannot be guaranteed to contain LDN or be safe. This is particularly true of LDN obtained from unregulated sources on the internet (15).

## How is LDN administered?

LDN is regularly administered in liquid form, with the most common single dosage being 1ml. It is taken using a syringe, such as those used to give medications to infants, and its form is similar to that of a general cough medicine.


It is also available in capsule form at 3mg and 4.5mg doses or as sublingual drops, which are a higher dose to liquid LDN and are used by people who have trouble swallowing. The drops are placed under the tongue with a dropper.

LDN is also available in a cream format, which is suitable for people who experience difficulties in taking the treatment via liquid, capsule or sublingual drops (14).


## Potential side effects

According to the LDN Research Trust, many people who take LDN will not experience significant side effects, if at all. However, sleep disturbances can occur if it is taken close to bedtime. They also state that in less than 10 per cent of people with MS, some symptoms may initially become more severe or more prolonged than usual, sometimes for several weeks. Rarely, symptoms may persist for two or three months before the benefits of LDN are achieved (14).

Your prescribing doctor will usually start the treatment of LDN at a very low dose and increase this gradually, making sure any increase does not cause, or at least helps to minimise, adverse effects. If you do experience any unpleasant side effects after



**I take 3mls of LDN, adjusting dosage when needed. It has stopped my heat intolerance and twitching legs but has not stopped progression**



starting LDN treatment, talk to your prescribing doctor. They may consider reducing the dosage for a period of time before increasing it again.

## Other considerations

While LDN is reasonably well tolerated, you should consult your GP, MS nurse and/or neurologist if you are planning to start LDN treatment. The LDN Research Trust state that this is particularly important if you are taking herbal medicines, multiple medications or have renal or liver failure (14).

You should always provide the prescribing doctor with your full medical history, so this can be accounted for prior to a prescription being authorised.

Furthermore, while LDN does not directly interact with steroids it can impede the effectiveness of opiate-based painkillers (14).

It is also salient to note that various studies have shown LDN to be compatible with MS-specific treatments such as disease modifying therapies (DMT) and does not alter any standard liver, kidney or blood parameters (16).

## Further information

### LDN Research Trust

This is a UK based not for profit registered charity that was created in 2004 by Linda Elsegood. Linda is a person with MS who has successfully used LDN to help manage the condition. The charity works closely with LDN prescribers, pharmacists, and patients, offering support and education. Their website offers a range of information, guidance and research on LDN and its therapeutic uses. [www.ldnresearchtrust.org](http://www.ldnresearchtrust.org)

### LDNscience

A public information project of the transatlantic not-for-profit organisation MedInsight Research Institute, whose mission is to empower medical professionals and patients with knowledge surrounding off-label treatments. LDNscience is dedicated to providing up-to-date information on the latest clinical trials and research which underpin how LDN can be used to treat a wide range of conditions. [www.ldnscience.org](http://www.ldnscience.org)



# About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

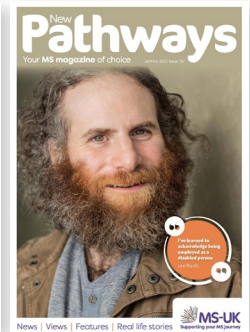
We will always respect people's rights to make informed decisions for themselves.

## The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.





## New Pathways

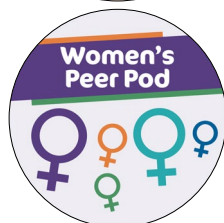
Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.

# About MS-UK

## Peer support service

Our peer support service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more [ms-uk.org/peer-support-service](https://www.ms-uk.org/peer-support-service) or email [peersupport@ms-uk.org](mailto:peersupport@ms-uk.org).





## MS-UK's online activities

MS-UK offers a variety of online activities for those affected by MS to stay active, connected with others and to manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. To get involved, please go to [www.ms-uk.org](http://www.ms-uk.org) or email [register@ms-uk.org](mailto:register@ms-uk.org).

## MS-UK E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created an accredited eLearning course that can help you do this. Visit [www.ms-uk.org/ms-awareness-e-learning](http://www.ms-uk.org/ms-awareness-e-learning) to find out more.

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## **MS-UK**

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