Choices



Low Dose Naltrexone



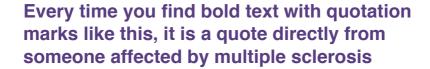
Multiple sclerosis information

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.



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Low Dose Naltrexone

Naltrexone is a drug developed initially to treat addiction to opiatebased drugs, such as heroin or morphine. It belongs to a class of medications called opiate antagonists (1).

Naltrexone delivered in lower doses – Low Dose Naltrexone (LDN) – has been used in the USA to treat the symptoms of autoimmune conditions, such as multiple sclerosis (MS), since 1985 and is now used in Europe and the UK (1).

The low dose method of taking naltrexone was devised and developed by the late Dr Bernard Bihari, from New York. Dr Bihari was a Harvardtrained physician who specialised in Neurology. (1).

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

LDN is used 'off label' as a treatment for the symptoms of many conditions including Crohn's disease, fibromyalgia, chronic fatigue syndrome and ulcerative colitis – conditions with an autoimmune origin, or potential autoimmune origin (2).

How naltrexone works

There are three elementary biological principles that underpin how naltrexone works, when given as a low dose solution (3).

Fundamentally, as an opiate antagonist, naltrexone is thought to inhibit endorphins – the body's natural painkiller. It is believed that by inhibiting endorphins, the body reacts by producing more. This increase in endorphins reduces pain and increases a sense of wellbeing.

Once LDN has been processed by the body, the elevated endorphins produced as a result can act together with receptors to assist in regulating cell growth and immunity (3).

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



Research into LDN

There have been many studies into the safety and effectiveness of LDN as a treatment for MS, mostly small trials, with mixed results.

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

A six-month phase II pilot trial of 40 people with primary progressive MS was conducted by Dr M Gironi, with the main purpose of looking at safety and tolerability. This study found LDN to be well-tolerated by patients who also reported an improvement of their symptoms, particularly spasticity, pain, fatigue and depression. There were also reported improvements to quality of life outcomes (4).

Another 17-week randomised trial was conducted in 2010 titled 'The effect of Low-Dose Naltrexone on quality of life of patients with multiple sclerosis: a randomised placebo-controlled trial'. In this trial, some people were given LDN and some a placebo, looking into the effects of LDN in relation to quality of life. There were 96 people enrolled in the trial – some with relapsing remitting MS and some with secondary progressive MS. This trial

demonstrated the safety of LDN. However, the results on LDN's effect on quality of life (as measured by physical and mental health) was not clearly proven, with no statistically significant differences shown between the LDN-dosed group and the placebo group (5).

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

A small-scale study titled 'Pilot trial of low-dose naltrexone and quality of life in multiple sclerosis' was published in August 2010 to evaluate the efficacy of 4.5mg of naltrexone, taken each evening over an eight-week period, on the quality of life of people with MS. Eighty participants with an MS diagnosis were enrolled, and 60 subjects completed the trial. The high rate of subject dropout and data management errors reduced the trial's statistical influence. The study found that LDN was well tolerated and serious adverse events did not occur during the trial. LDN was associated with significant improvement on a mental health quality of life measure. The trial concluded that LDN significantly improved mental health quality of life and suggested that further studies with LDN in MS were warranted (6).

The good news is that 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. However, more research is required regarding its long-term safety (7).

Accessing LDN in the United Kingdom

Naltrexone is licenced and used in the UK to manage opiate dependency (8), but LDN has not been licensed for the treatment of MS symptoms by the National Institute of Health and Care Excellence (NICE) and is not widely recommended for use to treat people with MS within the NHS. The use of LDN to manage MS symptoms is sometimes described as 'off-label' (9).

Many GPs and neurologists are cautious, given the guidelines



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

within the NHS, about prescribing LDN for the treatment of MS symptoms (10).

GPs are often unfamiliar with LDN and the LDN Research Trust have published a useful factsheet that may be helpful.

If you are considering LDN, the pack contains information for your GP or prescribing clinician. If you can obtain 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 gain a prescription privately (12).

It took many years for my consultant to agree to prescribe it. It was the MS nurse who finally persuaded her that it was helping patients in the USA. My own GP had to present a case for prescribing it. I still had to get the prescription from Scotland. I now get it on my prescription and have it delivered from my local chemist. It has been a long slog trying to get to this state of affairs

If you are unable to obtain an NHS prescription from your GP, your GP may be willing to write you a private prescription but will make a charge. You could also get in touch with a private specialist practice or one of the online GP services. You will be likely to 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.

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. I send the prescription to Dickson chemist in Scotland

If you have a private prescription you can obtain LDN from a specialist pharmacy. The LDN Research Trust hold a database of pharmacies around the world that are known to dispense LDN (11). You can read more about how to obtain LDN in the LDN Research Trust's factsheet (12).

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 (13).

How to take LDN

According to the LDN Research Trust, the majority of people using LDN will have a positive impact on symptoms quite quickly after starting treatment. They also say that in less than 10% of people with MS that are treated, increased symptoms may be more severe or more prolonged than usual, lasting sometimes for several weeks. Rarely, symptoms may persist

for two or three months before the appropriate beneficial response is achieved.

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 some of the more common adverse effects. If you do experience any unpleasant side effects after starting LDN, talk to your prescribing doctor about reducing the dose for a period, before increasing it again.

Some of the common initial side effects from taking LDN are increased fatigue, sleep disturbance (if taken at night-time) and increased spasticity, however, many people starting on LDN do not experience any side effects.

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

LDN is most commonly administered in liquid form. It is taken with a syringe of the same type used to give medications to infants. LDN is also available as a capsule 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 (12).

Special precautions

It is strongly suggested by the LDN Research Trust that you should talk with your GP, MS nurse or neurologist if you are taking herbal medicines, or multiple medications, or if you have renal or liver failure. If you experience liver issues you may need to be regularly monitored with additional blood tests.

According to the LDN Research Trust, LDN is compatible with steroids and some of the disease-modifying treatments (DMTs) for MS. If you are taking a DMT and are planning to start LDN it is suggested that you talk to your MS nurse or neurologist before starting.

Some medicines are not compatible with LDN – particularly opiate-based painkillers such as morphine.

If you are considering taking LDN, you should provide the prescribing doctor with your full medical history.

If you choose to start treatment with LDN please report any untoward or adverse effects immediately to your prescribing doctor so the treatment process may be re-assessed and modified if necessary (12).

Further information

If you are considering using LDN and wanted to do some further reading, then you could start with The LDN Book edited by Linda Elsegood (published by Chelsea Green Publishing Co). In 2016, the editor of MS-UK's New Pathways magazine reviewed the book and said that Elsegood had gathered together a host of experts on the subject, all of whom had written in a warm and engaging way. They felt that although MS shared a chapter with lupus, the information was exhaustive, covering many facets of MS without being patronising or boring and explained what LDN could do and how it might be doing it (14). This book, and a subsequent second volume released in 2020, are available to purchase online from a variety of retailers.

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 www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





Online activities

MS-UK offers a variety of online activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. Visit our website to explore and ind out more.

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 accredited Learning courses that can help you do this. Visit https://ms-uk.org/excellence-ms/ to find out more.

Sources

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Stay in touch

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