

Low Dose Naltrexone

A little-known, but potentially valuable therapy



A Report for *fight-parkinsons* members

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Low Dose Naltrexone and it's role in controlling Parkinson's

I was first made aware of Low Dose Naltrexone (LDN) in November 2015 by a Parkinson's colleague (thank you, Susan), and I've been researching it ever since.

LDN has fairly wide acceptance as a helpful treatment for autoimmune diseases, e.g. MS, and there are hundreds of testimonials from MS patients to its beneficial effects.

I have found a handful of testimonials for LDN by Parkinson's people, talking of their various recoveries after following this therapy.

Although a drug, LDN as it states by its title, is a low dose medication. It's well tolerated and there are no reported side effects.

On the plus side, it's a low cost therapy (£30/\$45 a month), compatible with Parkinson's medications and there are individuals with Parkinson's giving good reports of its effectiveness.

On a more conservative note, these reports on Parkinson's are limited to a few people. I would be more confident if there was much greater level of evidence.

In this short document, I present the available information, leaving you to make the decision upon whether LDN is for you.

Colin Potter

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What Is Naltrexone?

Naltrexone was developed in the 1960s to treat addictions, and was approved by the US Food and Drugs Administration (FDA) for the treatment of addiction to drugs such as heroin and morphine.

Human clinical trials in the 1980s confirmed that naltrexone decreased alcohol consumption through its action at the opiate receptors in the brain, where it blocks the release of endorphins denying the user their pleasure-seeking benefits.

Daily doses of 50mg of naltrexone are used to control the addictions of narcotics and alcohol abusers.



How Low Dose Naltrexone came to be discovered, and the role of pioneering physician, Dr Bernard Bihari

Like many drug success stories, LDN was discovered by accident.

Following the understanding of the efficacy of opioid antagonists (blockers) such as Naltrexone in the management of patients with drug addictions, it was two research scientists at Penn State University who discovered the unique action of LDN.

Doctors Ian Zagon and Patricia McLaughlin were studying neuroblastoma, a common tumour in children. During an experiment where they used naltrexone to block the effects of opioids, they discovered an unexpected effect – that a very low dose of naltrexone, on its own inhibited, the growth of neuroblastoma.

Yes, you've read this right, LDN shrinks tumours, (more upon this later in this document).

Following much more research activity and experimentation where they acquired complete knowledge of the mechanism of action of LDN, the scientists published their results in Science magazine in August 1983. The study was titled,

'Naltrexone modulates tumor response in mice with neuroblastoma'.

Enter Dr Bihari

That journal article captured the interest of many doctors, and set many a hare running. Here was a treatment which might help patients where nothing else was working.

Dr Bernard Bihari was, at that time, leading the treatment for AIDS in New York in his role as director of the Division of Alcoholism and Drug Dependence.

He began his own research and, once convinced of its safety, began to prescribe LDN to AIDS patients who had no other treatment options.

In a placebo-controlled trial with people with AIDS, it soon became clear that those on LDN were doing much better than the placebo group. There were many fewer deaths, and the immune system cell count was greater, in the LDN group.

By the mid-1990s, with an even greater understanding of the role played by LDN in autoimmune diseases, Dr Bihari began prescribing LDN for MS patients and other autoimmune diseases.

This pathway eventually leads to Parkinson's which, for many, has its origins in a weakened immune system.

You can view an interview with Dr Bihari, <https://youtu.be/x54Jccr8GT8>.

How LDN works in autoimmune diseases

Dr Bihari began to conduct his own research into LDN.

The body pumps endorphins, a hormonal compound that is made in response to pain or extreme physical exertion.

When an animal is attacked it pumps endorphins to:

- relieve pain and fright
- shift blood from digestive system to muscles and brain
- boost immune system for healing



It's the role of endorphins in regulating the immune system that really captures our attention as LDN has the ability to markedly increase endorphin production.

Taken just before bedtime, LDN temporarily blocks the production of endorphins. The body then wakes up, wondering where its endorphins are, and goes into overdrive boosting endorphin production by as much as 300%.

The elevated levels of endorphins boosts the immune system, restoring its proper function and thereby stopping the attack cells from attacking themselves (the hallmark of autoimmune disease).

MS, lupus, rheumatoid arthritis, eczema, Crohn's disease, psoriasis are some of many autoimmune diseases reported over the last 30 years to benefit from LDN.

How LDN works in autoimmune diseases

How LDN works with Parkinson's

We've already read that LDN greatly increases the body's endorphin production which then boosts the body's immune system. For those Parkinson's people whose origins of their disease lies in an impaired immune system, LDN should have a positive impact.

I've read, also, that LDN has antioxidant properties which offer protective benefits against neurodegenerative diseases, where chronic inflammation is an underlying cause. I have yet to find corroborative evidence, though.

What is not in dispute is the number of reports from Parkinson's people of the beneficial effect of LDN upon their symptoms, and its ability to hold back their disease's progression.



LDN: No reported side effects

There have been a few research studies into LDN and its use in certain immune conditions. These showed LDN to be safe and effective.

There are thousands of long term, autoimmune disease users of LDN; they report no side effects.

The regular LDN users published in the Parkinson's case reports all refer to the absence of side effects.

LDN is compatible with Parkinson's medications

Some very good news about LDN is that it can be taken in conjunction with Parkinson's medications.

So, it's not a matter of either / or; you can take LDN with your present Parkinson's medications, until you feel an improvement in your symptoms.

Then, you can decide whether you wish to reduce your Parkinson's medications. We recommend that you do this in consultation with your physician.

LDN is generally compatible with all other treatments or medications, with these following few caveats:

Use of any narcotic-containing pain medication during the same few hours (about 5 hours) of LDN's activity is unwise because LDN will block that drug's effect.

Use of immunosuppressant medications for any length of time will act to counter LDN's benefits, most of which are based on its ability to normalize the immune system. This is particularly relevant to anyone who has had an organ transplant.

LDN is available only following prescription by a doctor. You should make the doctor aware of your present medication or any changes in your medication.



'She was also able to reduce her dopamine-analogue medication by two-thirds, relieving the depression that it was producing'.



Why you won't be hearing about LDN from your doctor

Naltrexone is a drug approved for treating addictions at a dosage level of 50mg. It's approved because it has gone through the hugely expensive and time-consuming trials required before regulatory approval is awarded.

So, Naltrexone is an approved drug and is considered safe. As such, doctors can use it for what's known as 'off-label' use.

In the case of autoimmune diseases and Parkinson's, the low dose application of naltrexone is such an 'off-

label' use of a drug.

LDN has been the subject of numerous, small-scale trials by doctors and researchers. It has been used, successfully, over 30 years with tens of thousands of patients with autoimmune diseases.

But, your physician is unlikely to:

- a) have heard of LDN
- b) prescribe it for you

This is because doctors operate within a system which prescribes branded drugs, which have been through the regulatory process at specified doses for specified illnesses.

All evidence of small-scale research and patients' testimonials will be considered 'anecdotal'. For the majority of doctors, 'anecdotal' means inadmissible, and they are most unlikely to prescribe LDN.

This doesn't mean that there aren't doctors prepared to prescribe LDN. There are, and these can be found on the following pages of this document.

So, if you are looking to ease your symptoms and arrest the progression of your Parkinson's, it's likely that you'll need to take matters into your own hands and contact a doctor knowledgeable of LDN.

Lexie's Story

Back in 2008, Lexie Lindstrom, in her own words, was suffering from the following Parkinson's symptoms:

- Severe anxiety
- Chronic urinary incontinence
- Constipation
- Fatigue
- Pain and stiffness
- Illegible handwriting
- Dragging right foot
- No arm swing
- Loss of sense of smell
- Voice soft and shaky
- Inability to handle work-related stress



She rated her quality of life at 2/10. Having conducted research into potential treatments for Parkinson's and found LDN, it took a year of badgering her neurologist to prescribe it before her doctor relented on the basis 'it wouldn't do any harm.'

In early 2010, one week after starting LDN, Lexie says she 'felt good' and her 'severe anxiety' went. Thereafter, every time she saw her neurologist Lexie 'felt better and better'. At the time of her interview with the LDN Research Trust in 2014, Lexie ranked her quality of life at 9/10 with all symptoms 'improved tremendously or reversed entirely.' She reported:

- No fatigue or daytime naps
- No foot drag
- Pain gone
- Bladder issues resolved
- Sense of smell returned

You can listen to Lexie's story here, <https://www.youtube.com/watch?v=-M4tgBtUajl>.

Listen to others' testimonials

Celia - <https://vimeo.com/123481728>

Rachel - <https://vimeo.com/119671054>

Deirdre - <https://vimeo.com/113727748>

Hannah - <https://www.youtube.com/watch?v=TMbQN4avTmY&feature=youtu.be>

How and Where to Get LDN

You can attempt to persuade your doctor to prescribe LDN, which some people manage to accomplish by saying they accept personal responsibility.

Alternatively, you can go to a doctor familiar with LDN, who is prepared to prescribe it.

To find an LDN prescribing doctor anywhere in the world, go to either of these sites:

http://www.ldnresearchtrust.org/LDN_Prescribing_Doctors, or

<http://www.ldnscience.org/find-a-doctor/>

You can find a list of UK doctors at www.fight-parkinsons.org/parkinsonsrecovery.

Many of these doctors will provide a prescription following a telephone conversation.

Compounding Pharmacists

LDN is a prescription drug that is made by compounding pharmacies.

To ensure that you receive the right quality of LDN, you are strongly recommended to use only compounding pharmacists who

are recognized by the two leading LDN charities.

You find a recognized pharmacies on either of these two lists:

http://www.ldnresearchtrust.org/LDN_Pharmacists where there is a list of compounding pharmacies around the world, or

http://www.ldninfo.org/index.htm#How_can_I_obtain_LDN, where there is a list of pharmacies in the USA, Canada, and the UK.

They all ship it to you promptly and are inexpensive.

UK Compounding Pharmacist

The premier UK LDN compounding chemist is Dickson Chemist of Glasgow. You can contact them here:

<http://www.dicksonchemist.co.uk/HowdoesthisWork/Default.aspx>.

Dickson currently ship LDN to any EU country, and any other country upon request.

What does LDN cost?

LDN is a low-cost medication (typical for a generic, unbranded drug).

You should expect to pay no more than £30 (US\$45) for a month's supply.

Will LDN work for you?

This is the question we can't answer – yet!

Whilst there are a lot of case studies reporting the effectiveness of LDN with autoimmune diseases, we have limited reports to hand on its role in countering Parkinson's.

Until we have collected that evidence (you have a role to play here; see below) you are obliged to make your decision on the information provided. You can, of course, consult a LDN-prescribing doctor.

In LDN's favour is its low cost, its compatibility with Parkinson's medication and lack of side-effects.

This suggests that you have much to gain and very little to lose by giving it a try.



Tell us – we'd love to know!

If you decide to proceed with LDN, we'd love to know.

By keeping a diary of your experiences and changes in your symptoms, and by sharing that with us, you will help us build a body of knowledge about LDN and its effect upon Parkinson's.

We promise not to divulge any personal details. By sharing your experiences, you will help fellow Parkinson's people.

Write to me at colin.potter@fight-parkinsons.org.

Useful Links

The following are links to charitable / not-for-profit organisations who spread awareness of LDN:

www.ldnscience.org

<http://www.ldn-international.com>

<http://www.ldnresearchtrust.org>

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