

100
REASONS
WHY

YOU SHOULD
KNOW ABOUT

LDN

Low dose naltrexone



Produced by LDN Research Trust for
International LDN Awareness Week
19-25 October 2009

Is
low dose naltrexone
(LDN)
benefiting
these conditions?

Multiple Sclerosis
Ankylosing Spondylitis
Crohn's Disease
Hepatitis B
Chronic Fatigue Syndrome
Fibromyalgia
Peripheral Neuropathy
Hashimoto's Thyroiditis
Goitre
Psoriasis

These sufferers
testify
"Yes it is"

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an old drug
 a controversial treatment
 patient testimonies of success
 across a wide range of diseases linked
 by immune system dysfunction
 but

YOU won't hear of it and
 YOU won't be offered it

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THIS IS OUR GIFT TO YOU
YOUR DONATION HELPS US
CONTINUE TO GIVE

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'200 Reasons Why'
is in production
We hope you'll be in it

1

Adrian, UK **April 2005 - Secondary Progressive Multiple Sclerosis** **2006 - LDN**

I was diagnosed with Relapsing Remitting Multiple Sclerosis in April 2005.

My symptoms got gradually worse over a period of two years, then I had a bad relapse and my Neurologist sent me to hospital.

After an MRI and a lumbar puncture, the Neurologist gave me the news that my MS was probably Secondary Progressive, and I was discharged within a week.

My wife found the Multiple Sclerosis Society website shortly afterwards, and I started to use it daily. During a conversation with a man called George, I heard about LDN and started to research it further.

I thought this drug might help me, and I desperately sought a way of getting it. The usual channels, that is; doctors and neurologists; didn't want to hear about it, so I contacted someone off the website and spoke to them, and she kindly gave me Linda Elsegood's number.

Linda gave me all the information I needed, and it was finally sorted out about 3yrs ago.

Since starting on LDN, my life has changed for the better. I no longer experience relapse after relapse. The fatigue has improved, and I've started to feel well again. I've even started to drive again, after 8 months of being unable to.

During one of my earlier relapses, I'd lost most of the use of my left hand, but one night about 3 months after I started on LDN, I felt a strange feeling, like an explosion in my fingers, and suddenly, I'd regained almost all the use of my hand.

Since starting LDN I've had no relapses. I have had a few bad viruses, but I've fought them off and returned to being as well as I was before.

I truly believe my i.s. now functions very well. I now walk, with crutches, and I'm able to drive a manual car. I have independence, and I can get out when I want, and no longer spend months being housebound.

All this improvement started with LDN, and coupled with my now weekly visits to an MS therapy centre, I'm feeling as well as I have in years. It's true that I get the odd bad day, but it's only a day not 8 months!

2

Adrienne H, UK
1977 - Multiple Sclerosis
2004 - LDN

I was diagnosed with MS in my late twenties, some 32 years ago.

Having secondary progressive MS now, my condition continued to deteriorate and I am now 'wheelchair-bound', unable to weight-bear.

I was getting worse and worse at an ever-increasing rate. During my HBO session at my local MS Therapy centre five years ago, I was talking to a fellow member who had just started taking Low Dosage Naltrexone (LDN). Her positive experience -- being able to walk instead of using a wheelchair -- inspired me to ask my doctor if I could be considered to take LDN, showing him the research that had been done on the drug.

3

Alan Harvey, UK
1997 - Multiple Sclerosis
2004 - LDN

I had numerous problems before I was diagnosed, but as I was fit and active playing tennis at a high standard I discounted them. Things came to a head when my left leg became very heavy after a hard set, by the time the second set was over I had great difficulty playing at all, my GP arranged an MRI scan and consultant appointment.

I saw the consultant before my scan, he examined me and said he was 95% sure what was wrong with me but would wait for the scan result. I asked for the diagnosis and was amazed when he said I had MS. The scan confirmed his diagnosis.

It's difficult to remember exactly what happened 12 plus years ago when I was diagnosed, but I do remember researching MS and being terrified reading the information I found.

During the year after diagnosis I spiralled downwards and finally hit rock bottom with a crazy failed suicide bid!

As I could not play tennis anymore I was introduced to bowls, and that game saved my life. I found I could compete with able-bodied players on a nearly level playing field. In fact I have played for England in the Para Olympics.

Over the years I was given no medication except Procarin. I've tried most alternatives, such as 'Goodshape's' formula and numerous vitamins. Don't know if any of them worked as I was still progressing downwards, but I tried them anyway.

Then I read a report on LDN about 5 years ago and contacted Dr Bob Lawrence to try it.

The results were amazing!! All my symptoms improved and my fatigue disappeared. Before LDN, I could only play 1 bowls match, then go to bed. Now I can play 2.

I am now nearing my mid 60s, and I can do most things others of a similar age can do, even though I have MS. My GP is amazed, but still will not prescribe.

4

Amanda B, UK

2005 - Secondary Progressive Multiple Sclerosis (SPMS)

2006 - LDN

I was diagnosed with Secondary Progressive MS 4 years ago and I did not know about LDN until 3 years ago at which point I started to get it prescribed.

Before LDN I was suffering bladder problems fatigue and brain fog but since taking the LDN all of that has stopped.

Over the past few weeks I have been having a lot of pain with my back so I have had to come off my LDN as I have had to take Co-Codamol for the pain but today I have noticed that for the first time in 3 years I have got a cold so today I have decided that the LDN has kept colds at bay.

I wish I had known about LDN at the beginning, but the medical profession did not know anything about it.

5

Annmarie B, Wales **1972 – Multiple Sclerosis** **October 2007 – LDN**

In 1969, I had a TB vaccination. I was only in my teens, but from that time, my health became erratic.

I continually felt 'wrong'. In my first year sixth, I was absent from school for weeks at a time and whilst I managed to take my 'A' level examinations, my results were disappointing. Everyone, including myself, believed that it was stress-related.

I went to college but once again seemed to be making regular visits to the doctors. Eventually, I was given tranquillisers - as once again stress was diagnosed. I managed to finish my first year but only a couple of days into the summer vacation, symptoms flooded in fast and furiously. My handwriting was practically illegible: I couldn't hit the right notes on the piano; I couldn't walk in a straight line, drink from a cup; parts of my body were numb or had 'pins & needles' - and I was talking with a slur.

At the end of the summer (1972), I had a lumbar puncture and was diagnosed with MS. I was given a course of cortisone injections and no other treatment. At the time I had a few minor symptoms, but nothing that stopped me from working - including running my own business and having 2 children - a time I felt really well. For many years, I was never fully convinced that my diagnosis was correct.

I went back to full-time work when my son was 8 months old, in March 1988. I'd been working long hours and didn't realise I was pregnant for a 2nd time, until I had a miscarriage. I really wanted to spend more quality time with my 3 year old son, so I semi-retired from work in 1990. Not long after, my mother-in-law was diagnosed with bowel cancer, and passed away in December 1992 (within a year of the birth of our daughter).

In 1993, I had a car accident and suffered whiplash. I had problems with legs from that time, increased fatigue, broken sleep etc. In 1996, I had an MRI scan which confirmed lesions, but we did not know if they were from the original attack in 1972 or were more recent.

In 1997 I had another car accident: My car hit an oil patch and careered off the road hitting a fence. Unfortunately, a concrete post was behind the fence. My car ricocheted back over the road and landed in a garden. I was concussed and suffered whiplash again!

The period between 2003 and 2004 was a particularly bad time. My mum had a major stroke. Visiting and caring for her involved travelling to Birmingham every weekend for a year. She passed away in June 2004 and my dad passed away 5 months later, from a broken heart. Then a very good family friend passed away 5 months after that from prostate cancer, and our dog was run over in May 2005.

I was very run down and tired, and I couldn't seem to improve and get well.

In November 2005 I had my 2nd ever relapse - with symptoms that were worse than when I was first diagnosed!! I was unable to walk for a time and had real problems with my left leg especially. I attended an MS Clinic in Cardiff and was assigned an 'MS nurse', but was discharged by June 2006, with no follow-on treatment - but I wouldn't have accepted any anyway!!!

At the time I had brain fog and very bad balance, was unable to walk more than a few steps without help, had extreme fatigue, and after standing for a time found that I was doubling over unable to hold myself upright, etc, etc. I know that I wasn't as poorly as others I saw at the MS clinic but I did feel that I was being sent away until I was!!

All my nurse offered was a blue badge (which I accepted) and a walking stick (which I did not!!). Seemed to me, she had a shopping list and was just ticking it off as I deteriorated. I could do that myself!! I felt I was being left to get worse.

Over the following year or two I was extremely depressed, frightened, and felt very alone. I continued deteriorating and felt there was no hope, and that I would soon be in a wheelchair.

I had a shoulder operation in September 2007. While I was recovering I began checking out MS on the internet and I fell upon LDN. When I found the link to Dr Bob Lawrence, I rang him, had a long chat, and the following week my husband took me to Swansea. I spent 2 to 3 hours with him talking about anything and everything concerning LDN, MS etc. There was no downside as far as my husband and I were concerned, and I started taking LDN at the beginning of October 2007.

My local doctor won't prescribe LDN, but she's watching me very closely. As I continue to improve, I can't see how she can hold out indefinitely.

I also take the vitamins, minerals and other supplements Dr Bob suggests. I found a brilliant physio (originally for my shoulder) who is now helping me to re-pattern my brain to walk better and I've recently joined a T'ai Chi class. I eat healthily - but misbehave quite often.

I can honestly say that from the first LDN tablet I took, my problems and symptoms started to alleviate. I know this doesn't happen for everyone, but it's been 7 months and I'm feeling fantastic - a different person from the sad, depressed being who visited Dr Bob all those months ago!! Perhaps it's because wasn't taking anything else before I started on LDN, or because of Dr Bob's supplements, or maybe both.

I have to sing praise to both Dr Bob and Joyce, his right-hand woman!! I've emailed them most days and always had a same-day response - it's easier than ringing and getting the engaged tone. Dr Bob and Joyce are there to help and advise whenever, whatever - even when it's not connected to LDN!!! It really helps knowing Dr Bob takes LDN because he too has MS ... he is somewhere to hang your hat!! In fact, if I lived closer I'd gladly be going there every day to look after them whilst they look after all of us!!

The effect of LDN has been extremely subtle over the time I've been taking it. Just this last week, I've realised that the pains in my left leg are subsiding, slowly but surely. I've

even worn shoes with a heel the last couple of days - haven't done that for over 5 years!!

I haven't gone back to bed during the day these last 3 months - in fact, we've just acquired a puppy, so I've been getting up between 6 and 6.30am every day!! I'm not doubled-over anymore after I've been standing. My walking improves with each day, and I am now confident enough to take Syd (the puppy) for a walk without someone to hold on to.

LDN has changed my life - it's stopped me from being frightened and has given me hope for the future - and I know it will continue to. I intend to run again and I haven't done that for 15 years!!! Everyone with an auto-immune disease should know about LDN!!

Not every day is good!!! I reckon that in any one month, I have a 'wrong' week but it's nothing in the grand scheme of things. I think of it as a time of transition - my body readjusting and realigning to the subtle changes brought about by LDN.

Update - 25 September, 2008: At the end of July, I had a fantastic hypnotherapy session with Ted Heath who, to-date, has worked with over 300 people with MS. What a fabulous couple of hours! What a positive experience! What a lovely man! I was convinced that counting back from 100 was no problem. I managed 97!! He re-patterned my walking, gave me various triggers for different problems and gave me exercises to strengthen my muscles - all that and took delivery of a parcel whilst keeping Syd (our dog) amused!!

Well, in August we went to Rome for 5 days and I organized four 3-hour walking tours for the family - giving me an enormous mountain to climb if I did them, but knowing that I didn't have to if I felt unwell. Before I relate the outcome, I have to admit that I went well-armed!!

I completed all 4 tours - one of the Coliseum and Forum, a walk along a section of the Apian Way and around the Catacombs, a city tour and a tour of the Vatican and Sistine Chapel!! Admittedly, I had some funny moments, but then I either took a breather or hung on to hubby, son or daughter - whoever was nearest! But, importantly, I didn't slow the group down, so was I pleased with myself, LDN and especially Ted!!

About 2 weeks ago, I had another of my funny weeks when things just didn't seem right, but then up another notch I went. A couple of days ago, I walked around 2 supermarkets without the trolley that over the last 4 years I've needed to hang on to as I couldn't propel myself forward. More often than not, my daughter has had to pull me along on any necessary shopping trips whilst guiding me so that I don't bump into anyone - she's in her teens and an absolute treasure!!

I was out visiting our son who is now renting a house and in his 2nd year at uni. I asked if he thought my walking and balance had improved. He had, but didn't want to jinx me by saying anything!!!

Also, this week I was out walking Syd with my husband, and we both noticed that I no longer have to hang on to his arm. I can walk again unaided.

I've just taken Syd on a walk by myself. I didn't stop once - pretending to admire a flower, tree etc whilst waiting for my legs to start moving again. I walked there and back just like everyone else does. I'm ecstatic!!!!!!

So, my balance and walking have improved amazingly in the 3 months since writing 'my story' and my sleeping is phenomenal - rarely waking in the night to toilet trot and asleep as soon as my head hits the pillow - and it's a restful sleep. In fact, my husband describes me as 'dead to the world' in seconds.

To sum up, it's now been 4 years since I had my second ever exacerbation, which left me bedridden for a time. I spent the next 3 years getting more and more depressed and convinced that I would soon be in a wheelchair.

In September 2007, a sorry figure visited Dr Bob and Joycie and after a good few hours talking decided there was no down side to taking LDN.

One year later with the help of LDN, GABA, other supplements, a reasonable diet, Dr Bob's good counsel with trusty Joycie and not forgetting the amazing Ted, I now have a life to look forward to.

The best decision ever!!!!

I'd love to keep you posted and if there's ever anything I can help with, please let me know.

Update - 25 March 2009: I can't believe it's been 6 months since my last update - which means 18 months have gone by since I started taking LDN.

The one major change in my regimen is that I began taking LDN 4.5ml liquid instead of tablets in February 2009, when new legislation meant I could no longer get my tablets from Dr Bob Lawrence. This has surprisingly been a positive move - I've found both falling asleep and having sleep that is even more restful has been the outcome!! My only problem with the liquid has been practical - using the syringe supplied with the liquid - much too fiddly, with most of the liquid that should be in the syringe dribbling down my fingers. But, that is easily solved - I now use a teaspoon!!

I've also been a little remiss and not taken my minerals and vitamins religiously - it always happens in the dark dreary days of winter when everything seems such an effort. But, now the sun is shining and the days are getting brighter and longer, I should have the impetus to behave again!!

I continue to hiccup along the way - it happened again a couple of weeks ago - lots of pain in my left arm, side and leg, even interrupting my sleep. I've found that I can lessen the pain if I'm well wrapped and snug, and then I sleep through - a simple solution that is working. Over-the-knee socks are worth the investment too!!!

The left side 'stuff' has been around since I was first diagnosed in 1972 but the emphasis has changed over the years. In 1972, I had pins/needles/electric shocks in my left arm - often lying on it so that I could get to sleep but nothing in my leg.

Since the mid 90's I've had niggly pains/shocks around my left hip sometimes cascading into the front of my upper leg.

About six years ago (during a stressful period in 2003), it all started to become more pronounced and travelled through my left arm, around my left hip and then into the front of my left leg all the way down to the top of my foot.

My left leg always feels extremely cold - I always think of a slab of wet cold fresh fish!!

Dr Bob Lawrence suggested taking Malic Acid about a year ago, which does help enormously with the pain. Now its intermittent - if I try to hurry, it becomes more pronounced so I just don't hurry :-)

I've always felt my body, especially waist down, belongs to two different people - normal sensation in my right side, stuff and nonsense in my left!!

My test for years, as I don't have a fish slab, is to lean my legs against the outside of the toilet, obviously in succession - it's cold, smooth and almost feels wet!!!! Right side fine, left side goes haywire, like an electrical storm. Am I barmy !!!! One day, there'll be no storm.....

Having said that, my walking continues to improve, albeit small steps only - but I do have to be mindful otherwise I trip where there's nothing to trip over!!

I've had a couple of massages that have really helped and also invested in a set of pedals - not a bike with a seat, just pedals, and I sit on an upright chair - quite a contraption but it works!! At the moment I'm not using any resistance but intend to introduce it gradually. I've had maybe 2 sessions of physio since Christmas, compared with before Christmas when it was practically once a week. Sometimes, I even walk Syd, my dog, from the house to the local park rather than driving there.

So, once again, my update is positive and I'm still enthralled with LDN!! I'm also really looking forward to the 1st LDN European Conference in Glasgow at the end of April. I'll be there waving my flag!!!

6

Atif A, Scotland November 2005 - Multiple Sclerosis November 2008 – LDN

I am in my late 20s, and I was diagnosed with MS in November 2005.

My MS symptoms started way back in 2000, which was my first year of University. I used to get the 'craziest symptoms', which always used to show up around exam time.

I remember the worst time was in May 2004 when I became cross-eyed, and the right side of my face became numb!! I used to always be paying visits to doctors to explain the numbness and try to find out why it was happening. I'd be given an appointment at the hospital to get CAT scans and blood tests, but once again, no result would be obtained.

The doctor would tell me to try and stay calm and "pray to God"!! In November 2005 I had a Lumbar Puncture, and was diagnosed...FINALLY!! The doctors at the Southern General told me that it was the 'Relapse Remitting' type of the disease, and that I would be started on treatment very soon.

I was given the Interferon injections, which I had to take deep in the muscle. The interferon was not having much of an affect though, so the dosage was increased to 3 injections a week. Life on that treatment was painful. I found myself not only having to fight the painful symptoms of MS but also having to take other drugs to combat the side affects of the Interferon!!

Life for me had come to a stop. I knew that there had to be an answer to this illness somewhere. I used to do the research on the internet on a daily basis to try to find a solution. Around the same time, I was attending the 'newly diagnosed' group at the Southern and we had a talk by Dr Gilhooly about this drug called naltrexone, taken in low doses (LDN). I spoke to the nurse after the talk. She was extremely sceptical and said it was just lies.

So I dismissed thoughts of LDN, but still continued on with the research. It was in November 2008 when I started researching LDN again, and the effects of this drug. I then discovered an article written by Dr Bob Lawrence on the positive affects of LDN. At the end of the article was a telephone number. I dialled the number and spoke to Dr Lawrence. I found out that Dr Lawrence himself had MS and was on the LDN. He told me that I had nothing to loose and that if it didn't work I could always go back on the Interferon.

I started the LDN treatment at 9:30pm that night, beginning on 3mg. That very night, at around 11:30pm, I started getting sensation in my fingers!! Even though I was experiencing the full sensation on my hands, I still could not believe it.

My initial thoughts were that this has to be a placebo type affect. Surely no drug of such success can be unheard of. The very next morning when I got out of bed and took my

first steps, I realised this WAS the answer I'd been searching for!!! I could walk around a lot easier.

I spoke to Dr Lawrence on a weekly basis and he told me to increase the dosage slowly to reach the amount that my body could handle. I now am taking the maximum amount, 4.5mg every night, and I feel almost as if I am CURED!!

My prayers have been answered, thank God. LDN has virtually no side affects of any kind, and it's had such a positive impact on my life. I've got my life back together again. I can enjoy sitting out in the sun without pain. I can work out in the gym for long periods of time and work up a sweat without pain. I can think more clearly and I'm performing a lot better at university. I haven't had to take any more painkillers because the pain has vanished!!

I was lucky to find out about LDN, come across Dr Lawrence's number, and be given it through my GP. I'm also one of the lucky who achieve better than expected results with LDN.

But there must me many more people out there that are still living life on Interferon and other drugs. Please let LDN be made available to all that need it.

7

Audrey H, UK
1997 - Multiple Sclerosis
March 2007 - LDN

There's not much to my story really. I am in my late thirties now, but I've had MS since I was young (when I had diplopia for a few weeks). I also had burning sensations in my legs. In my early 20s I had a lumbar puncture and MRI. As it was during the late 1980s, the doctors thought it better not to tell me, even though they wrote in my medical notes that they 'suspected' MS.

Throughout my twenties I had relapses, but I wasn't diagnosed until I ended up in tears in front of a compassionate GP. He sent me for another MRI, and then the two MRI's were compared. MS was confirmed.

Throughout my thirties my relapses got progressively worse and despite following a healthy diet I got to the point where I couldn't see, couldn't stand up, and was falling over - mainly because of balance problems. I had fatigue that prevented me walking very far. I couldn't even peel a carrot, and was generally feeling suicidal and hopeless. During this time, I never tried any other drug.

I seemed to be on a steep decline. I had five relapses with no intermission and no short breather. The last went on for six months. I wasn't sure what was happening but my MS was really progressing.

If I went for a walk it was like the plug was pulled out after a short distance. My energy was zapped. I could barely walk and had very, very little energy to do anything or go anywhere. I would awaken as if I had done a marathon the day before. My right hand would keep me awake at night from nerve damage - it had been numb for six years.

One of my relapses just six months prior to LDN left me unable to drive, with difficulty walking, talking, eating and preparing food. I had terrible fatigue. No energy and no ability to make something to eat - with no one to help, including my husband. I found it difficult to go to the toilet to empty my bladder. I dropped whatever I touched literally.

My balance became bad and I would constantly fall over. I would go into remission, only to have another relapse straight away. I had double vision and needed an eye patch. I sprained my ankle 5 times because I couldn't see. I had problems with cognition, no clarity of thought – often called 'brain fog' by others with MS. Then I had a bladder infection and I had to take antibiotics and both my legs went numb and stiff with spasticity.

Then I found out about LDN. My neuro and two local GPs would not prescribe LDN, but fortunately, a Harley Street GP came through for me. At the time of starting LDN, I had spasticity in my legs and general fatigue. Within a matter of days I felt like a new woman. It was as though I had been given my life back. The spasticity left, and the fatigue lifted.

I noticed a difference within a few days. I began three days before I had an appointment with my MS nurse. I actually walked to the hospital - something I definitely couldn't have achieved before starting. It must have been 1 mile at least. My mood was much happier and I noticed a difference from the word go. I found myself dancing to the radio and realised my fatigue had disappeared.

I saw my GP and he noticed my walking was much better. The previous time I saw him I was walking with a stick. Today my right hand (which suffered from nerve damage and numbness) feels markedly better.

This is one of my diary notes: 'I have been taking LDN for a month and already I have virtually no symptoms including previous bladder retention. My energy is amazing. I am sleeping the whole night through. Yesterday I got up in the morning, walked the dog, and went for a 1km swim. I went for a strenuous bike ride, walked the dog, made lunch, tidied the house, walked the dog again, went shopping, picked up my husband from the station, walked the dog yet again, and still had enough energy to make something to eat. I find if I plan, I can still spend the day somewhere like St Albans or Windsor and still find energy to drive home, walk the dog and socialize. The most noticeable difference is the reduction in numbness, pins and needles, bladder retention, sleeping the night through, energy levels and probably more. All in the first month.'

Taking LDN has helped me get back on my feet and build up my strength sufficiently to stop my rapid decline.

On the way to my second appointment with the GP who originally prescribed my LDN, I got off the train at Marlebone and ran all the way to Harley Street. I remember running down the platform at the station and beating everyone to the barriers. I thought that was pretty good considering I'd spent six months incapable of much at all not that long ago.

I originally paid for the LDN myself, but later went to my own GP and asked if she would prescribe LDN. She said, "Wow you look fantastic", and prescribed it for me. Two male GP's at the same local practice had previously turned me down.

I've now been on LDN since March 2007, 16 months. Despite a short exacerbation, which wasn't as severe as previous relapses, I'm still active and full of life. My only side effect is constipation, which I've had since starting LDN. Nothing I've tried seems to help. Over a long time this may result in other problems, but who knows. Also, I noticed if I take my LDN at bedtime, I can have nightmares, so I experimented with taking it a bit earlier, and it worked - no more nightmares.

I now have a border collie who is extremely active and keeps me busy. More than anything LDN has given me hope.

Update – January 2009: I've had diplopia for as long as I can remember. When I look to the far left, right, up or down. If I do exercise it gets a bit worse. I saw my optician recently and he thinks I had it as a child, just didn't notice. I haven't had a relapse and it's been like this the whole time I've been on LDN.

I am trying to be careful with diet and lifestyle but Christmas is a difficult time of year. I've just had a birthday celebration and I was as good as gold. I ate pigeon and venison. I had an Elissa test and it revealed I had a problem with most proteins. The only proteins I eat at home are hemp seeds and quinoa.

The constipation problem disappeared soon after starting on the Best Bet Diet (BBD), and I got rid of my nightmare problem by taking my LDN a bit earlier at 10.00pm instead of 11.30pm.

I have just joined a gym for three months so I hope to make the most of it. I don't think my border collie is going to be too pleased!!

It's now July 2009... to update my case I never did go to the gym and I didn't continue with the BBD. My Elissa test told me to exclude everything I was eating but to give up so many foods would be impossible. I now eat everything, gluten, dairy and the odd glass of wine.

My health has been good and I didn't have a cold all winter until May. I don't feel like I have MS. I am even attempting to have a baby, something I never thought I'd hear myself say. I'm closer to the end than the beginning of my childbearing years, so it's a bit late, but I am putting my trust in the LDN.

8

Bev K, USA **2004 - Multiple Sclerosis** **2005 - LDN**

My husband was diagnosed with MS in 2004. He had not long turned 40. He was diagnosed fairly soon after his first definitive symptom, which was Nystagmus. MS was confirmed after a brain MRI and a lumbar puncture.

Of course we were shocked, and right away the Neuro advised him to begin Avonex. We were given all the info - a huge folder of paperwork. When we took it home I spent a couple of days going through it all and finding out how much it would all cost. Living in the US with no health insurance is a scary thing. I'm British and was used to the NHS, not without its problems, but compared to living with no health providers at all, it seemed wonderful by comparison.

When we found out the Avonex would cost us over \$1,000 a month, we were horrified. How could anything cost so much! THEN, I started to hunt online for an alternative. I found out that Avonex and indeed all the injectable MS drugs, were not only expensive but fairly ineffectual. My husband always laughs at me for being online so much and using the computer to research so many different things. When I came across LDN and we started talking about it, he changed his tune!

I wish now that I'd started to make notes of the whole process, as my memory is not so great on how we progressed after that. I know I found the Yahoo LDN group and asked a lot of questions and found info to print up and take to the Neuro.

We told the Neuro that before my husband would try the Avonex, he wanted to try LDN. It was a treatment we could afford, and it was obviously less invasive than an injection each week. We left the info with him and returned a few weeks later. He said he'd rather my husband start on the Avonex, but agreed to him trying the LDN for a while.

We had to tell him how to fill out the script (we still do actually!) and we sent the script off to Skips Pharmacy in Florida.

He started off with the first batch of LDN at 1.5mg, and within a month was at his present dose of 4.5mg. I think he's missed one pill once in the whole four and a half years.

We still battle occasionally with the Neuro. Now he says my husband probably has 'benign' MS and that's why he's still so well. It's not true, but whatever works for him! Have to be gentle with the Neuros!

My husband has had a brain MRI each year since diagnosis. No new lesions have appeared since he started on LDN. Many of the lesions he had have either gone or are inactive. He's had no new symptoms and no relapses. He still has some cognitive

issues, and a little balance problem. When he's stressed or tired his Nystagmus kicks in a bit, and he has periods of fatigue.

It costs us under \$70 for a three-month supply - one pill at bedtime each night. He's had no colds or flu or any of the 'things that go around' that I always get - his immune system is superb!

He works as a stonemason every day. It's a physically demanding job and he's outside in the elements all day. It's hot because we live in California. He's now in his late 40s and as strong as an ox!

LDN is not a cure. It hasn't repaired any of the damage he got before he was diagnosed. But he hasn't got any worse and for us, that is fantastic. I know he will never stop taking it - regardless of any other drugs that may appear in the future.

The neurologist works at UCSF where some limited clinical trials were conducted recently. When we ask the doctor how many other patients he has on LDN, he's cagey about it and I can see he doesn't really want to talk about it. When we're in the waiting room we see people in wheelchairs, with walkers, shuffling and limping along. It's maddening and heartbreaking all at once. I want to go and talk to them all and tell them to check out LDN. I want to slip a note into their pockets. I want to shout out, 'LOOK at my husband, SEE how well he is'.

I recently got diagnosed with Fibromyalgia and plan on starting LDN soon too. I also have Hashimoto's Hypothyroid so am hoping for some good results.

I am passionate about spreading the word as I know many others are, so hopefully there will be power in numbers, and eventually it won't be such a battle to get our healthcare providers to open their minds to LDN.

9

Dr Bob Lawrence MRCS LRCP
Dietary Research Ltd, UK
1986 – Multiple Sclerosis
2001 - LDN

My first symptoms of auto-immune disease actually started long before the onset of the MS. This was an acute onset of lumbar back pain during the summer of 1967, my final year in college. At that time, I was just 26 years old and attending Plymouth Technical College while taking three 'A' level examinations. These were in preparation for entry into Bristol University as a medical student.

I was otherwise very fit, active, and capable of either walking or running many miles. As a poverty-stricken student it was economically often essential to walk to and from the college each day. At other times, I would regularly walk ten miles or more, either for pleasure or simply visiting friends, some of whom lived several miles from my home.

The back pain was the first indication of the often relapsing-remitting nature of auto-immune disease as the pain would simply occur or disappear completely without any apparent logic or reason.

It was later that same year that I was to suffer a tragic road accident when, whilst riding my motorcycle, I was hit by a careless driver who turned right suddenly without checking his mirror. I was thrown against a lamppost, seriously damaging both legs.

Due to this injury I was forced to remain in hospital for five months, which obviously delayed my planned entrance to Bristol University Medical School in September. A year later, in 1968, I was still walking with a full leg calliper when I began attending lectures in my chosen subject at Bristol.

My subsequent progress through medical school was often difficult due to the obvious disabilities resulting from the injuries and it was this constant level of pain that finally contributed to my eventual failure at the final examinations in 1973.

Undaunted however, I and several other of my equally unhappy, and unsuccessful, student friends immediately applied to attend the examinations in London for the external degree of MRCS LRCP, a joint examination held by the Royal College of Surgeons and the Royal College of Physicians. This I completed and passed in March 1974.

On Starting my first pre-registration job as a doctor in Merthyr Tydfil, South Wales, I soon found the work quite demanding due to my poor walking ability and an average working week of 100 hours.

In response to this increasing level of stress I soon developed a further recurrence of the back pain, now obvious as ankylosing spondylitis (AS), with recurring thoracic and lumbar pain. In December of that year I bought my house in Swansea and, with my wife, Pauline, and two young sons, took up residence in the quiet residential area of Treboeth.

It was during the latter part of my employment at this hospital that I also developed an acute inflammatory condition of my right eye. Late one evening, I happened to run into the Sister in charge of the ophthalmic outpatient department.

With years of experience in ophthalmics she immediately recognised the condition as serious and promptly called the on-call ophthalmic physician. He quickly confirmed the diagnosis as uveitis, an inflammatory, auto-immune condition of the eye, known to be associated with the occurrence of ankylosing spondylitis.

The sight-saving treatment for this was the immediate and regular use of steroid eye-drops, applied every hour, plus the use of atropine eye-drops twice daily, which caused the pupil to dilate, making vision blurry and indistinct. This treatment was continued for about three months before the problem was completely resolved.

This problem further confirmed the prior diagnosis of ankylosing spondylitis due to the common association between these two conditions.

After completing my first six-month post in general medicine at Merthyr Tydfil I transferred to Neath General Hospital where I was to conduct my efforts in the art of

general surgery. The surgeon in charge of this surgical unit was known to be somewhat eccentric, driving an ancient 1936 Rolls Royce. He was also a notorious tyrant who expected his junior doctors to be present on the wards at all hours, both day and night. Needless to say, this continuing level of stress gave rise to further bouts of back pain associated with the AS.

My next job, starting in August 1975, was as Casualty Officer at Singleton Hospital, Swansea.

This was busy, but not with the level of stress previously experienced in General Surgery. At times the work was intense, with several hundred patients being seen each day, all attended by just three doctors. It was during my duties at this task that I experienced what may now be considered as my first symptom of MS. This was the sudden onset of a divergent diplopia, or double vision.

I was subsequently seen by an ophthalmologist, who, without offering any explanation of why this might have occurred, simply gave me a small card with two separate images, on one side a picture of a cat, and, about three inches away, on the same side of the card, an image of a tail. The aim of the exercise was to focus the two images so that they coincided, placing the tail on the cat.

This amusing little exercise kept me busy for the next three months before the diplopia finally resolved, with normal vision re-established as a single image once again.

I completed the job at Singleton in February 1976, when I decided to try my hand at anaesthetics. After being shown the various techniques involved in inducing anaesthesia I was considered safe and fit to start my own anaesthetic list within just one week.

I continued this work until 1978 when I decided to transfer to General Practice, starting work in a small practice in the Brynmawr valley, in Gwent. I left this post early in 1979 and I made use of Aircall, working mainly at night or at weekends, when regular GPs chose to use this emergency cover instead of attending the calls themselves.

Eventually, I found a longer-term post at a practice in Clydach, one of the outlying districts of Swansea. Having the convenience of a local post I was at last able to take advantage of the opportunities to do some gardening and also some restorative work around the house. I decided to take on the task of renewing the concrete of the driveway and an area at the back of the house.

Anyone who has ever used ready-mix concrete knows that the mix sets very quickly so it was a frantic race against time trying to complete the task before it all went hard. This was the time when I noticed the first real sign that I now recognise as MS. One half of my right thumb had suddenly become numb.

I initially attributed this to the demands of my heavy days work but, as time went by, within a few days, the other half of the thumb had also gone numb. Next was the first half of the first finger, then the numbness of this finger became complete, then the next finger was affected, then the next. Within about ten days the whole hand had become quite numb.

I did initially assume that this would eventually resolve itself, but it has only been since starting the LDN, in 2001, that the hand begun to regain its normal sensation.

I later noticed, when completing another section of the concreting, trying to carry bags of cement from the boot of the car, that I was no longer able to lift the bag as I had been able to do so many times before. I became seriously concerned when I had to ask a neighbour for assistance to carry the bag from the car to the back of the house.

During my time at this current post it was an occasional benefit when all the doctors in the practice, a total of four, were able to take advantage of the generosity offered by many of the drug company reps. This often involved lunch, a large steak, which I enjoyed with relish. I did begin to notice however, that following the meal, within about twenty minutes I would experience a dramatic increase in back pain.

The journey back to the practice to complete the remainder of the days work was also found to be an acutely painful experience as every minor jolt or bump in the road sent spasms of pain down my spine.

After this initial observation it did not take long to realise that this pain was only occurring after eating beef, in one form or another. It also became equally apparent that on those occasions when I chose either chicken or fish, the pain simply did not occur.

This was not a surprising revelation to me as I had suffered recurrent migraine since a child and I had become aware that certain foods were instrumental in initiating the migraine attack. Some examples of such foods I had come to recognise as chocolate, oranges, or cheese.

I decided to investigate this observation more thoroughly and, while browsing in a local bookshop (this was long before the later and convenient access to the internet), I discovered a book, which discussed this very same principle.

This was entitled, 'Diet for Life, A Cookbook for Arthritics'. Written by Mary Laver and Margaret Smith, the book described how avoiding certain foods could improve symptoms of arthritis. Mary Laver had apparently suffered with rheumatoid arthritis for several years and had developed a dietary regimen which she found effective in eliminating her symptoms.

The foods which it was considered necessary to avoid included all of those that I had found detrimental in both migraine and the back pain I had experienced.

Needless to say, I bought the book and followed the advice offered. As anticipated, while following this advice, the pain resolved and ceased to be a problem.

Early in 1981, after completing my year at this practice, I applied to attend for an unpaid attachment to the local Maternity Unit at Mount Pleasant Hospital, Swansea, the purpose of which was to gain sufficient experience to qualify for my obstetric certificate, required to carry out obstetric work in general practice.

After completing the required thirty deliveries I was awarded the appropriate certification to conduct this work, but I was never to make full use of this qualification, as subsequent job opportunities seemed to become increasingly rare and even more difficult to find. I reluctantly returned to Swansea to face a series of further locum posts, which were to continue into 1982.

At that time, late in 1981, I had noticed an article in one of the many free medical newspapers, which referred to the opportunity of a career in the Royal Fleet Auxiliary, a fleet of civilian manned merchant ships, maintained and provided by the Ministry of Defence. These include tankers, munitions and dry stores ships, troop and logistics supply ships and helicopter support ships. Within the merchant navy it is a rule that any ship carrying more than 100 men was required to also carry a doctor.

The article was offering the opportunity of joining this service. With the added opportunity of travel to various locations around the world, and the security of permanent work, this seemed very appealing. I made my application but it was mislaid and I was enrolled too late to join the initial task force to the Falklands. A subsequent application was successful and I was eventually posted to serve on the tanker, RFA Olwen, which I joined in Gibraltar in 1982.

Numerous deployments followed. During this period I was to experience the first signs of an increasing dispirited fatigue characteristic of MS that was to become more severe later.

My final deployment was on the Olwen. Nearing the end of my term I grew aware of certain changes in my level of fitness. My walking was no longer as steady; I had also become aware of episodes of profound fatigue in more recent months, when I seemed not to have the energy to even pack a suitcase in preparation for leaving the ship.

The feelings of increasing weakness and lassitude that I had previously experienced on the Resource became not only more severe, but more prolonged. These deep and pervasive feelings became not only physically, but also emotionally and intellectually draining, affecting not only my mood but also my processes of judgement and rational thought. This overwhelming fatigue seemed to sap both the spirit and the soul, leaving an empty loneliness that, by whatever means, could not be filled.

I was by this time, aware that during my time on the ship it had become necessary to abandon many of the requirements of the restricted diet that I had been previously following. Unfortunately, on a ship, it was no longer possible to choose the menu in the way that I had been able to while ashore. I therefore found myself occasionally eating those foods that I had previously attempted to avoid.

In this way, I was once again able to demonstrate the adverse effects of such a non-selective diet, when my symptoms clearly began to get worse as I strayed from the desired path of suitable foods.

Thus, as my symptoms became progressively worse, I seemed to know that this was to be my final trip with the RFA, which was also to culminate in a somewhat anxious episode when, during our return to the UK early in 1986, the ship's engines failed during our transit of the Southwest Approaches several hundred miles from the tip of Cornwall.

The ship was subsequently left adrift for three days while the ship's engineers worked frantically trying to establish the necessary repairs. It was at such a time that it may be realised how dependent we were on the various ship's systems: with no power there was no water to wash or to drink, the toilets did not flush, there was only emergency lighting to see by; and food could not be cooked.

For three days we lived on sandwiches, drinking emergency bottled water supplies, and flushing toilets with buckets of water lifted from over the side of the ship. The greatest concern however was the risk of collision with other ships. It was cause for celebration with the power restored, when all the various ship's systems came back on line. With normal services fully restored we quickly made our way back to the UK to dock in Portsmouth.

On reaching port, we were once more able to reconnect to all the routine shore services including luxuries such as telephones and television. I remember reading news of a female patient in America, apparently diagnosed with MS, who seemed to recover from her symptoms after having all her mercury amalgam fillings removed and replaced with silicate fillings. This was obviously of interest to me as I had, for some time, begun to consider the diagnosis of MS in myself.

I was later to undertake this same procedure in the hope that my symptoms too would be equally resolved. The process however, although considered advisable, failed to make any apparent difference to the further progress of my symptoms.

With this increasing sense of doom and coincident symptoms associated with my cigarette-smoking habit I resolved to, at least, bring this habit to an end. As ships doctor I was able to order a quantity of Nicorette, nicotine chewing gum. I then planned to use up my last packet of duty-frees, at 27p for twenty, and, at 8-30 pm, on the 27th February 1986, in company with the Senior Radio Officer in the officers mess, I smoked my last cigarette.

Having seen many others who had made such similar claims the SRO was not convinced that my resolve would be successful, but after 23 years as a non-smoker, I think I have won the battle.

When the inevitable craving came to greet me several hours later I was prepared with my nicotine gum. Chewing this hopefully, I remained in some doubt that it would be effective. I was however, surprised that the demand, that intense craving to place yet another cigarette in my mouth, disappeared like magic. On each subsequent occasion when this urgent demand re-occurred, I would simply chew on the gum for a few minutes and once more, I was free of the craving that had maintained this damaging habit for so long.

I continued the use of the Nicorette long after I had left the ship when, after using the gum for about four months I felt confident enough to change the nicotine gum for plain chewing gum. I continued with this for a few weeks more, then abandoned the gum, and the habit, forever.

I now know that had I continued smoking, this habit would have contributed greatly to the further decline of both the MS and my remaining physical abilities.

Soon after this, my term of attachment to this ship was completed and I left the Olwen, and the RFA for the last time. I felt particularly demoralised when leaving the ship as, by this time, I felt so weakened that, making some excuse of a trivial injury, I was forced to seek help just to carry my suitcase down the gangway to finally leave the ship.

On reaching home I soon made an appointment with my GP to seek a neurological opinion regarding my worsening symptoms. This eventually resulted in an appointment

with my local, but not very well informed, neurologist, who immediately, and falsely, assured me that I did not have MS.

I insisted on further investigation and after a CAT scan, a visual evoked response test (VER), and a lumbar puncture, it was finally confirmed that MS was, in fact, the diagnosis.

I fruitlessly inquired about diet and nutrient therapy, of which I had read much in my basic research, but this was entirely denied and briskly condemned as placebo effect. I left the hospital intent on pursuing my own line of research and inquiry.

I thus established a routine of attending the hospital medical library at Singleton where I was able to use the full range of research journals and books available there.

At that time there was no facility for computer searches of journals etc. so the only means of tracking down appropriate articles was to look up any interesting sections of the monthly compendium of scientific references, the Index Medicus.

I was to continue this process ultimately for years until I had established a clear and effective means of minimising my symptoms.

During this period I had also decided that, on the basis of some of the research that I had revealed, I would consider the use of certain minerals in the treatment of MS. I surmised that both zinc and copper might be of relevance in this condition when I found that both these minerals contributed to the production of prostaglandins, important cell mediators in the expression or resolution of inflammation in disease.

I also joined the MS society and asked their advice. I was sent a bundle of information sheets including details of an advised low-fat diet. I subsequently joined the local branch of the MS Society, which met twice-weekly, on a Monday and a Thursday.

I noticed here that the Centre provided tea and lunch for those wanting it, but I was surprised that the meals often consisted of many of the foods that the MS Society had already advised against.

During this period of early searching, when I attempted to find as many sources of advice and information as were available, I was unfortunate in suddenly developing a bout of acute pneumonia. Immediately my MS symptoms become much worse and I was promptly admitted to hospital. During my stay, with an appropriate course of antibiotics, I had the opportunity of discussing some of my research with the neurologist who had made the initial diagnosis of MS.

I was quite shocked when he seemed totally unaware of much of the research that I had discovered, and even denied the association between various different auto-immune conditions which had been declared as common. This conviction that neurologists are not always the most expert at dealing with MS has been reaffirmed to me on many occasions since.

With my recovery and subsequent discharge from hospital I was free once more to seek out further help from other sources. I was dismayed by the apparent lack of concern over the most suitable diet, and absence of more positive support at the local MS Society Centre, I therefore decided to leave and joined the newly opened ARMS (Action and Research into MS) Treatment Centre in Llansamlet, Swansea.

This had been opened and equipped with funds raised by the local ARMS charity group, the members of which had raised over £35,000 in donations.

The Centre had a six-man hyperbaric chamber capable of being pressurised to an equivalent depth of water of 33 feet. In practice, most patients using this treatment, a method that had been in use since about 1940, were treated at pressures lower than this.

Traditional intermediate pressures used are usually, expressed in equivalent depths of water, at 8 feet, 16 feet or 24 feet.

I started using this method of treatment early in 1987. Following the introductory 21, almost daily treatments, I slowly became aware that I was beginning to feel some benefits. I felt more vigorous, stronger, and more mentally alert than I had been.

Up until this time I had been suffering initially severe levels of depression, weakness, disturbed sleep, an increasing, stumbling disability and mental lassitude. On many days it had taken huge effort to motivate myself to the actions that would finally reveal the methods that would resolve so many of my symptoms.

One morning, while watching the morning television on ITV I was drawn to a presentation of a new book by a professor of biochemistry from Reading University. This was Professor Derek Bryce-Smith, an expert in the study of many common minerals and their effects on both health and disease.

The book was entitled 'The Zinc Solution', jointly written by Derek Bryce Smith and Liz Hodgkinson, described how zinc deficiency was a common occurrence in many conditions, including auto-immune disease, atopic problems and other conditions, such as anorexia nervosa. I was fascinated by these revelations as, together with MS, these were the conditions I had been researching and testing in association with the possibility of deficiency of this very mineral.

Within the book Professor Bryce-Smith also described a simple test that he had devised, the zinc taste test. This was based on the premise that zinc is essential in maintaining the senses of both taste and smell. Thus, in a state of zinc deficiency it would be expected that these functions would be diminished.

This simple test involved tasting a solution of zinc sulphate, at a concentration of 1 g/litre. The duration of the test was confined to just ten seconds because during this time the zinc would be rapidly absorbed onto the taste buds of the tongue, thus enhancing their function and taste perception.

Four different grades of response were defined denoting four different levels of deficiency or normality.

I was so intrigued by these details that I bought the book and subsequently wrote to Professor Bryce-Smith, describing my interests and observations regarding MS. I was flattered when he replied to my letter offering to visit Swansea and test any willing members of the local HBO Treatment Centre.

This meeting was duly arranged when the professor gave a short talk about his work with MS and zinc deficiency. We then tested about thirty MS patients who had

attended. The professor also described how his research had also shown a consistent deficiency of both copper and vanadium.

He explained that these minerals were important in many vital functions, including immune activity, adrenal function, preventing oxidative stress, and maintaining both mood and energy. The results of the zinc taste testing showed that every single patient with MS was shown to be at least moderately deficient in this vital element.

As a comparison we tested some of the partners or carers of these patients, when most of these showed a relatively normal response. It was of interest however, that some of these also showed deficiency at various levels, showing how common zinc deficiency actually is.

The most dramatic response was when testing the nurse in charge of the Centre, who tested so strongly positive that she later declared that she was still aware of the taste three days later!

We then planned a simple research project providing supplements of zinc citrate, copper, and vanadium to a number of volunteers to see what response was obtained.

This study however proved to be less than ideal as many of the volunteers, keen and enthusiastic at the beginning, ultimately failed to maintain their compliance with the recommended treatment and within weeks or, at most, several months, largely gave up the treatment. Those symptoms that improved in those that continued the supplements long enough reported increased energy, less depression or fatigue, improved appetite, and improved sleep.

With this supporting evidence available however, I remained convinced of the method and have continued these supplements ever since. With additional supplements, also determined by my continuing research, I was subsequently able to maintain my MS in an almost complete state of stability with just a slow rate of progression for about 15 years.

As my research continued I discovered, one by one, new connections and links in a long chain of facts that together formed a rational method of combined diet and nutrient therapy.

This I decided to test by offering it to others who might be willing to consider my advice in dealing with their problems, as I had, to a great extent, already dealt with my own.

Thus, in February, 1991, I set up the company, Dietary Research Ltd, as a service to others, offering advice in the treatment, not only of MS, but numerous other problems, such as arthritis, post-viral fatigue syndrome, irritable bowel syndrome, and other atopic or auto-immune diseases.

I contacted the Evening Post newspaper, which agreed to send Ms Jill Forward, an independent, free-lance journalist to write a story about my work and intentions. Ms Forward subsequently came to my house, where we discussed my research and intended purpose in finding a means of resolving MS symptoms. She then wrote a very positive article which, when presented in the Evening Post newspaper raised a large number of inquiries from the local community.

With these first inquiries I started my work in earnest, discussing the problems

presented to me and offering advice as I considered necessary. I found the work fascinating because, as I had found in general practice, determining the fundamental nature of a problem and treating it effectively by simple means, the ideal in medical practice.

I had always found it most informative to discuss individual problems extensively with each patient, which is why I disliked the intensive time-related appointments of general practice. I found greatest satisfaction, and gained important information, from inquisitive discussion, often at length. These often prolonged discussions would frequently reveal details and facts that would directly or indirectly provide an immediate answer to the treatment needs of that patient. I was also learning that disease was often related to simple nutritional deficiencies creating problems that so often were traditionally treated with drugs.

These drugs, often addictive, sometimes toxic, and occasionally dangerous, would then create even greater problems of side-effects, which were also then treated by even more drugs. The result is an ever more complicated spiral of poly-pharmacy which benefits only the drug companies while leaving the patient in a state of drug-induced dependency.

I considered it infinitely preferable to use simple means, such as diet, vitamins or minerals, which may be of equal or even greater benefit than the drugs they replace. Two such examples are the use of vitamin E, effective in reducing thrombosis risk by a much greater degree than the low-dose aspirin traditionally used for this purpose. The other is the simple mineral selenium, which has been shown by numerous studies to reduce the risk of developing cancer by at least 50%.

In addition, I was often able to gain an additional benefit by learning of the methods that others had independently found to be also of benefit. It was often therefore possible to learn as much from the patient as I was able to offer them in advice.

My biggest expense at this time was continuing to reach those who might possibly want my services. This initial impact of the newspaper article was soon dispelled and I rapidly found it necessary to place regular advertisements in newspapers and magazines.

Such advertising was very expensive: £40-00 per week for a small newspaper advertisement, and about £400-00 for a similar advertisement in a national magazine. With the additional cost of a part-time assistant I soon found that I was regularly losing about £2000-00 per year in excess of the income gained. This overall expense was conveniently provided by my service pension from the RFA.

By 1994 an additional personal problem also became of greater significance. Since about 1988 I had experienced an increasing degree of angina, chest pain associated with a slowly diminishing circulation to the heart. This increasing occurrence of chest pain led me to seek advice from my own GP, who recommended admission to Cardiff hospital for a coronary angiogram.

Before this could be done I was put on a vasodilator drip with an intravenous cannula inserted in my left hand. This continuous infusion was intended to reduce the chest pain, which continued intermittently. After a few days however, I began to feel increasingly unwell. Blood samples were taken for bacterial screening, which showed a severe form of septicaemia demanding a powerful antibiotic treatment.

After a number of days of worsening symptoms the angiogram was deferred and further tests carried out. These showed a continuing infection with no resolution of the septicaemia. After trying a second antibiotic, when the infection again appeared to persist it was deduced that the likely fixed source of the infection was the cannula itself.

This was duly removed and my temperature, and the infection, resolved within twenty-four hours. I continued the antibiotic for a few more days to ensure complete eradication of the infection, when the angiogram was at last booked and carried out.

This showed only moderate narrowing of some of the branch arteries of the coronary circulation and I was offered two drugs, one a calcium antagonist, and the other a beta-blocker. I soon became aware of the dramatic side-effects of the beta-blocker when my sleep became grossly disturbed, with bizarre dreams for the maximum of two hours sleep I would attain, plus daytime hallucinations that made me wonder if I was actually awake or not!

The beta-blocker was thus changed for one that did not cause these strange side-effects and I was finally discharged home.

After some days I became aware that the drugs, although temporarily effective in reducing the pain, had no prolonged effect in preventing its recurrence. I therefore surmised that, as I was already taking a moderate dose of vitamin E, a potent vasodilator, and that the nature of the angina could be due to vasospasm of the arteries of the heart, I might gain a significant benefit by doubling my dose of this simple vitamin. I promptly increased the dose from 400iu to 800iu, when almost instantly, within just a couple of days, the pain had gone entirely.

I abandoned both the drugs, that had proved so ineffective, and I have continued with this high dose of vitamin E with no further recurrence of the pain ever since.

My logic, and the results I obtained, were later reaffirmed by a study at Addenbrooke Hospital in Cambridge, conducted in 1996, when a double blind, placebo controlled trial of a single daily dose of vitamin E, 400iu, in patients already having suffered a heart attack, showed a 79% reduction in further risk by taking this simple vitamin.

I continued my work, now gradually limiting the range of problems I chose to deal with. Eventually, I was dealing almost entirely with just MS, plus a few related conditions, such as colitis or rheumatoid arthritis.

Slowly, as my work increased, my reputation grew and, by 1997, as I had begun to make increasing use of the internet, I had become sufficiently well known to be able to stop advertising entirely and just rely on word-of-mouth recommendations to gather new inquiries.

It was this connection with the internet that was to later reveal the final link in the treatment regime that was to complete the stability of my MS.

This was the discovery, in late 2000, of low-dose naltrexone (LDN), a method initially applied in significant numbers by Dr Bernard Bihari, a New York physician. At that time Dr Bihari was treating about 70 patients with a variety of complaints, by this treatment method.

On first reading mention of this apparently simple method, first noted in the web forum of an internet advisor referred to as 'Goodshape', (actually an ex American Airforce doctor), I was naturally suspicious of its claims.

I therefore spent more than a year both investigating and testing the method by first obtaining a supply of the drug in 50 mg tablet form. I also obtained from the manufacturer, Dupont, a list of research references describing the various ways in which a liquid preparation could be prepared.

Choosing the most suitable method, which gave a stable suspension, with an appropriate shelf-life of about 60 days (when stored at 4 deg C or below) I finally started testing this on myself over a number of months.

After some initial difficulty by the chemist in preparing the mixture I was able to establish a regular supply, which I used over a period of several months. After confirming its response and freedom from side-effects I later made the decision to order 5000 capsules from Bigelow Pharmacy in New York. These were initially all at a dose of 4.5 mg, and with lactose filler, as advised by Dr Bihari.

I publicised details of the method in New Pathways, the bimonthly magazine of the MS Resource Centre. This article was published in issue 15, Sept-Oct, 2002, which, on publication, heralded a torrent of new inquiries, which initially, I found both encouraging and flattering. Obviously, I was not the only one who had heard of LDN.

Within weeks it was obvious that I would need to order a further supply. I therefore started placing repeat orders so that I could maintain an ongoing supply for those already on the treatment. The numbers treated slowly increased and so the size of the LDN orders also necessarily increased in proportion. It soon became obvious that the initial dose of 4.5 mg was not suitable for everyone so I later also requested an additional supply of 3 mg.

A further problem also became obvious when a significant number of patients started to complain of muscle or joint pain within weeks of starting the treatment. This, I surmised, was due to the use of lactose filler and so I arranged for this to be replaced by calcium carbonate. This appeared to resolve the problem so I continued with this filler for several years with no complaints.

I also changed my supplier to Irmat Pharmacy when, on investigation, it became obvious that their prices were significantly lower than my previous supplier.

Continuing and increasing both the use of LDN and the range of problems that it might be used for I slowly increased the range of doses to provide six different sizes, including 1,2, 3, 3.7, 4.5, and finally, 6 mg.

The very low doses were used in the few cases that remained intolerant to the usual range from 3 to 4.5 mg. Only rare exceptions, about 0.5% of all those treated, were able to gain benefit from the extreme 6 mg dose.

Following some discussion on the internet suggesting that calcium carbonate filler was subject to clumping, thus reducing the rate of absorption of the drug, I later changed the filler to Avicel (methyl cellulose), an inert filler.

This principle of dissolution rate was also tested prior to the USA LDN conference in 2005 by Victor Fallah, the senior pharmacist at Irmat Pharmacy. He found no difference in comparative tests between all three different fillers, lactose, calcium carbonate and Avicel.

My current list of about 500 patients includes mostly those with MS, with a few suffering other auto-immune conditions, such as rheumatoid arthritis, ulcerative colitis, Crohn's disease, or psoriasis.

An increasing range of cancer patients have often shown a remarkable rate of recovery, in some cases with proven cancers actually disappearing completely. One of the most successful problems treated seems to be follicular non-Hodgkin's lymphoma. Currently, with five cases being treated, all remain stable, with no further relapses even after up to six years of LDN treatment.

It is my primary intention to bring this simple, and obviously safe, method to the attention of the medical profession. I pursue an active campaign of informing GPs of patients on this treatment, emphasising both the safety and effectiveness of the method, with the deliberate purpose of encouraging and inducing them to provide this treatment, at low cost, on the NHS.

It is hoped that the anticipated publicity planned to occur during LDN awareness week in October will advance these aims.

I am already greatly encouraged by the progressive increase in the number of NHS GPs and private doctors already using this method and I was recently delighted to attend the very first UK LDN conference in Glasgow on 25th April this year, generously presented and sponsored by Dr Tom Gilhooley, of the Wellness Centre, Glasgow.

The talks and discussions presented by the various very notable speakers clearly demonstrate the intense and increasing amount of work being conducted in the vital field of research.

The first speaker at the conference was Linda Elsegood, one of my first patients requesting to use LDN. Linda skilfully, and very capably, demonstrated the distinct effectiveness of this unique method. An inspiring and impressive presentation by Joseph Wouk also amply demonstrated the potential for recovery of this dreadful disease. Joseph has also written a book, 'Google LDN', that can be read online or purchased as a download from the internet.

An additional talk by Dr Phil Boyle, of Galway, Eire, also emphasised the extreme safety of this method, proved when he used the drug in company with a regimen of natural hormone therapy to effectively treat infertility in many women.

In 50 cases, in order to prevent such as late spontaneous abortion or stillbirth, the treatment was continued throughout the pregnancy, when not only was the method clearly shown to be safe, with no abnormalities of any kind demonstrated, but the babies born of the LDN mothers were actually found to be fitter, stronger, and even better behaved, than the average child.

This clearly confirms the safety of LDN when used throughout pregnancy in the treatment of other conditions, such as MS or rheumatoid arthritis.

Videos of all the talks and other links may be found on the conference website, www.glasgowldn2009.com.

10

Brenda M, Northern Ireland
DATE - Multiple Sclerosis
July 2006 - LDN

I come from a town in Northern Ireland. I started taking LDN about 3 years ago after hearing about its benefits, and I heard it straight from those who found it beneficial.

I had never heard about it before and was very interested to find out more. As soon as I got back from the MS conference where I had heard about it. I looked it up on the internet and researched it. I was told that there were no side effects once you got started on it and I was very intrigued.

I got Dr Lawrence's phone number and gave him a ring. All I had to do was go to my own doctor and get him to write a letter to Dr Lawrence telling him that it was okay for me to start the treatment.

I started it and within a few days of being on the treatment I felt a big difference. I had to self-catheterise morning and night and I had bad double vision at the time. Within one year I had no more need to use the catheter and my double vision had gone from 5 steps prism in my glasses to 1/2 in one eye.

It has helped me move on with my life a lot and it has helped me sleep a lot better. It still hasn't taken away the MS but it has helped me a lot. I am so glad that I take LDN, thanks to Dr Lawrence and a lot of his guidance.

I am grateful for LDN.

Bridget, New Mexico
2005 - Ankylosing Spondylitis
2006 - Fibromyalgia, Endometriosis, Raynaud's, Osteoporosis
1 May 2007 – LDN

I developed Ankylosing Spondylitis at age 10. I was diagnosed by the time I hit adulthood, then developed Fibromyalgia soon after.

I started LDN two years later on May 1, 2007, and I had a baby (while still taking LDN) the following year. I'm now in my mid twenties, am healthily breastfeeding my daughter, and wouldn't stop LDN if someone put a gun to my head.

My AS is in the 'Moderate to Severe' category, with almost every joint in my body affected, including jaw, fingers and toes, but not much fusion. The year before I started taking LDN, I was using a cane about 40% of the time, using a wheelchair occasionally, using the handicapped parking spot 100% of the time, and absolutely unable to even think about going to the mall. I had to drop out of my college classes because I could no longer write or draw. My doctor told me the Fibromyalgia is a secondary diagnosis . . . and that I probably developed it BECAUSE of the AS.

I had tried Remicade (broke a big flare but fizzled out and wasn't helping anymore), Prednisone, Methotrexate, multiple NSAIDs, and opiates (had a long-term relationship with Vicodin and Tramadol, with a nasty break-up) and several other things. When my doctor said the next step was Enbrel, I decided to try LDN instead, mostly because I didn't want to inject myself, and Remicade had already failed. A friend of the family had been telling us about LDN for a long time because it had helped her father with Parkinson's.

After one week on 3mg, my family noticed that I was moving more smoothly. After two weeks, I was absolutely ECSTATIC because my pain was cut down drastically, and I was running around in the rain chasing the sheep. Running, chasing, and rain had all been impossible before.

The second month I went to 4.5mg, and my improvement plateau-ed after about a month at that dosage. I'd say that my daily pain number before LDN was 7-9, and after LDN it's 2-4. When I overdo it, and send myself into a flare, the flare lasts a fraction of the time it did before (for example, 6 hours on the cane instead of 2 weeks on crutches).

I'm still nowhere near NORMAL, but now, 95% of the time, no one would know I have AS. I can go to Walmart now, without using the wheelchair, and I don't have to use my parking pass very often, and I even get to DANCE with my husband occasionally.

I worked at my job for about 11 months before anyone even knew I had AS. When I came in one day flaring, on the cane, everyone asked if I'd been in a car accident. Before, I'd have been on the cane for two days after going grocery shopping, or any

time it rained. I can stand in line at the bank or the post office now without crying. So this is a HUGE improvement.

And another thing worthy of mention... I took LDN all the way through pregnancy, and my daughter is amazingly healthy, smart, etc (really, I'm not just a proud mom, she really IS healthy and IS smart lol). It's even possible that LDN helped her, because I had lost 3 pregnancies before starting LDN, and this pregnancy went well and never threatened to miscarry. Now she's 10 months old and I'm breastfeeding her while still taking LDN.

My 16-year-old nephew put his 'Incurable' metastasised Medullo Blastoma Brain Cancer into full remission with LDN at 4.5mg. At least, his parents, his oncologist and I credit LDN with the 'miracle' turnaround. We don't have proof that it wasn't a direct intervention from God. The cancer had metastasised to his bloodstream and lymph system, and in October of 2007 they said he'd be dead by February 2008. He started LDN in early November 2007, and on January 17th 2008 was in full remission. He remained in remission until he died of an accident in May 2009.

My husband is also taking 4.5mg LDN for a mystery illness (includes seizures, tremors, high blood pressure, dizziness, vomiting, anxiety, and other symptoms) and he says he started feeling better within 3 days and now he feels 60% better than before LDN. He'd been sick for a year and started LDN in June 2009. He's in his late twenties.

So, here are three different LDN stories in one email! I think I may be the first AS patient to ever try LDN, and I know that my success with it is directly responsible for several of my AS friends trying it. I should really be the poster child. My life is SO much better. I could go on about LDN for weeks.

12

Carole ANON

May 2008 – Relapsing Remitting Multiple Sclerosis (RRMS)

Nov 2008 – LDN

This is a story about my success with LDN.

In May 2008, at just over 60 years of age, I was diagnosed with RRMS.

In late 2007, I needed to have back surgery, but through the MRI's ordered by my spine specialist, he told me I needed to have ACDF (anterior cervical discectomy with fusion) neck surgery right away because my spinal column was compressed to a dangerous degree.

He also noticed some lesions on my brain and spine and told me to see a neurologist. I saw a neurologist within a month and took more MRI's and an Evoked Potential test, plus a ton of blood tests.

The next visit he confirmed the diagnosis of MS and he wanted to start me on steroids right away to settle things down. He had his MS nurse discuss the so-called CRAB drugs with me and I went home with the literature to make my decision.

On my next visit, the neurologist asked me if I had decided which of the CRAB drugs to take. CRAB is an acronym for MS drugs... Copaxone, Rebif, Avonex and Betaseron. I told him I still had not decided what I wanted to do and that I did not want to rush in to a decision, since I did not get this MS overnight.

I spent an untold number of hours on the computer trying to learn all I could about multiple sclerosis. That was when I came across the lowdosenalxtrexone.org web site. After reading their wealth of information, I now had the answer to what I wanted to do. Now I had to find a doctor to prescribe it for me, and a pharmacy to compound it.

I first asked my neurologist if he would write me a prescription for LDN, but he refused. He told me LDN was not an FDA approved drug for MS. Well, it is an FDA approved drug, but it's approved at much higher doses, primarily in the management of alcohol and opioid dependence. Just like Sinemet is FDA approved for Parkinson's Disease, but was then found to help RLS patients like myself.

My next appointment with my Primary Care doctor was coming up, so I took her some literature and explained to her why I wanted to try the LDN. She glanced over it briefly (with much interest) and said she didn't think she'd have a problem with it, but she'd get back to me after checking it out. My next appointment with her came up about a month later. She told me she did not have a problem with writing me a prescription for LDN (which she did), as she saw nothing in it that could hurt me. I was more than happy to sign a waiver for her.

Next I had to find a compounding pharmacy. Lucky for me I ran in to my former boss at the grocery store, and in our conversation she mentioned she had to have something compounded and told me where to go. The pharmacy was only a few miles from my home! I think they mentioned that I was their first customer to request LDN. I began my LDN at 3.5 mg in Nov. 2008, then increased it to 4.5 mg 2-3 month's later. The cost was \$40.00 for a month's supply. My cost was only my co-pay of \$15.00 for a once a night capsule, AND NO INJECTIONS!!!

Now it was time for my next appointment with my neurologist, and I had to tell him I'd started taking LDN. He was silent for a few moments and I thought he was going to tell me to find another doc, but instead, he asked me if I wanted my PCP doctor to treat me (his MS nurse was also surprised he didn't tell me to find another doctor!). I said to him that I would love for both he and my PCP doctor to work with me as a team... to let me be his guinea pig. It would help both of us. He agreed.

Almost immediately I began seeing many of my symptoms either improve or disappear completely. The feeling of 'cement' and that tight, heavy feeling in my stomach and thighs, and the spasticity in my legs was nearly gone in one leg, and all gone in the other. My energy level increased tremendously, and the pain and numbness in my left jaw and neck disappeared.

I am still taking LDN. The constant tremors in my left shoulder and arm now only occur once in a while and very mildly, to say the least. My bladder control has improved considerably. What used to be hourly trips to the bathroom became only 2-3 times the whole night.

I fall asleep as soon as my head hits the pillow. I have not had a cold, the flu, nor any bronchitis in the last two years I did have those very vivid dreams/nightmares I read about some having when they first start LDN, but for the most part they pretty much disappeared. I also had what sounded to me like crickets chirping in my ears for many years... I hardly ever hear them anymore.

I am now a strong advocate for LDN. I tell everyone I can about LDN, including my doctors, anaesthesiologist, pharmacist, nurses, friends... anyone that will listen. The purpose of sharing my story is so others like me will know they have another choice... another avenue in the treatment of MS, and other autoimmune diseases and it's an inexpensive one that doesn't involve shots.

To those who decide to try LDN, I pray you will have as much success as I have had, and more. At least until the cure is found... there is another choice.

Blessings to you all.....

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Cristina G, UK
April 2003 - Multiple Sclerosis
March 2005 - LDN

I am working full-time in the software industry and I have RRMS.

My first relapse was Dec 1993, but I was not diagnosed until 10 years later.

My second relapse was in March 2003, and in April 2003 I was diagnosed with MS.

I then had relapses in Dec 2003, and again in Jan 2005. I started taking LDN in Mar 2005, and I have not had any relapses since then. I get tested for vitamin D every 6 months and adjust my vitamin D supplements according to the test result.

I take various vitamins, supplements, and 4.5mg LDN daily at bedtime. I do some exercises 5 times a week. I do not generally eat wheat and I eat very little pork (I have been tested and am sensitive to wheat, pork and cow's milk). I try to minimise my intake of saturated fats and maximise intake of fresh fruit and vegetables. I do not currently have any disability and the only symptom remaining from my earlier relapses is a mild bladder problem - mild urgency and some hesitancy.

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Christian C, UK
16 Mar 1995 - Multiple Sclerosis
29 June 2009 - LDN

I don't have Multiple Sclerosis (MS), nor take low dose naltrexone (LDN), I am just a witness to how LDN can change one person with Multiple Sclerosis in two weeks.

MS:

My mother was diagnosed with Multiple Sclerosis in 1995 with relapsing-remitting MS and over the first 10 years had many relapses until the MS was re-assessed as secondary progressive. I think it is fair to describe how MS has affected her before talking about the results with LDN.

She was a very successful businesswoman, and due to the MS, had to cut her career short and retire due to ill health.

MS is different for everyone. What primary symptoms does she experience today? Fatigue, tiredness, incontinence, self-evacuation, memory loss, inability to walk, fidgety leg (uncontrolled muscle spasms), but the end result is loss of dignity. Remember these

are her main symptoms. She is affected by a whole host of other MS symptoms, but as her son, these are the most visible to me. Imagine the need to urinate, but by the time you get to the bathroom you have wet yourself.

One thing that is very hard to describe to non-MS sufferers is fatigue, the usual response is 'I get tired too'. MS fatigue is very difficult to describe, and perhaps the closest analogy is having severe flu where you are so weak you can't get out of bed. She is a keen gardener, but on most days she does not have the strength to prune one rose.

This is what living with MS is like for her, and from my point of view, seeing my mother being slowly ravaged by this horrible illness is impossible to describe.

How we learned of LDN:

A fellow MS sufferer first talked about LDN about 12 months ago and the effects it had on him. Being cautious, we researched LDN, talked to our local doctor, and she asked her NHS MS consultant his views and if there was a trial, i.e., she played by the book trying to go through existing routes to try LDN. This proved fruitless.

With the help of the LDN Research Trust we found a very sympathetic consultant in London who is experienced working with MS sufferers. After examining her symptoms and reviewing her medical history he prescribed LDN. The dose started at 3mg for two weeks then moved to 4.5mg. This is being written at the end of week two, where she is still on 3mg.

Results after starting on LDN:

Initially she was understandably very nervous about starting LDN, as anyone is with a new medical regime, but her response to the LDN was almost instantaneous, and the main symptom that has been relieved is fatigue.

Now, remember the flu analogy above and when you recover it is such a relief and how you feel when you are back to firing on all cylinders.

Other symptoms are more manageable, because her fatigue has been greatly reduced:

- ◆ Sleep has improved, with her fidgety leg bothering her less.
- ◆ Walking has improved (she does not stumble from being exhausted).
- ◆ Walking has improved, so she can make it to the toilet.
- ◆ Her memory has improved.

Like the results Doctor Oliver Sacks experienced in 1969 with the drug L-Dopa (unsuccessful treatment of encephalitis lethargic), we accept the current results of LDN may not last and may wear off over time. We hope not, as the changes over two weeks have been outstanding. Not every day is a magical day, she still suffers from fatigue and the symptoms of MS are always there.

What I am doing:

I provide support by being there when needed to help both my parents live as normal a life as possible. As a side note, my holiday this year is a banger car rally around Europe of 2400 miles, to be undertaken in September 2009. The contestants are encouraged to raise funds for their chosen charity. As LDN has had such an effect and the LDN Research Trust has been so helpful and forthcoming, I will raise funds for them. It may not raise a large amount of money, but I know it will be greatly appreciated.

How LDN works:

LDN (3mg to 4.5mg) works by blocking the endorphin receptors for only a few hours and the body apparently compensates by creating more endorphins. Once the low dose naltrexone has been metabolised, the body is left with a 'normal' amount of endorphins, which consequently normalizes the immune function. This theory of LDN's mechanism contradicts the widely-held belief that autoimmune diseases are caused by an overactive immune system.

Conclusion:

I can understand the views and hesitation of the consultant. The main problem is the BMA has to use evidential medicine. This is to stop fad medicine and the Shipman's of this world. So for MS treatment, that means drugs to suppress the immune system to stop it attacking the myelin sheath.

LDN is the reverse of this, a drug that encourages the immune system. This is the very same immune system that is attacking the myelin and causing the MS.

What is needed is a full double blind trial of LDN. If the results back up the current experiences felt by people taking LDN, this will give the BMA another weapon in their armoury for the treatment of MS.

Who am I?

I'm a businessman in my mid thirties. I work in central London for a large international charity. I work in the IT department where I am responsible for a wide area network of over 300 sites with 5000 users. In my spare time I enjoy gardening, home improvement, movies and a good book.

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Christine R, UK
1977- Multiple Sclerosis
September 2006 - LDN

My sister in law first introduced me to LDN almost 3 years ago.

Where my sister-in-law worked, there was a young man who also had M.S.

One day she noticed how much better he was walking and asked him what he was taking. He then told her he had been taking a new drug called LDN for a few weeks. She asked for the details and who to contact to find out more information.

I made an appointment to see a doctor who'd been recommended and shortly after, started taking LDN at 1.5mg, with intent to slowly build up to the optimum dose of 4.5mg.

Prior to taking LDN I had no balance, my left hand would not straighten, my arms were weak, I used a Zimmer frame, was bent over all the time, and had constant fatigue.

After a few weeks of taking LDN, I could open my left hand and the strength in my arms had much improved. I was able to sew and do my own hair again. These are little things, I know, but they mean so much. My balance had significantly improved I could stand straight, not bent over all the time. The constant fatigue had also improved.

All progression of my MS has ceased since taking LDN, and I have only had positive benefits from taking it.

The doctor I have been seeing for the last 3 years is to retire very soon, and as awareness in the UK for the use of LDN in the treatment of MS is very poor, I now fear for the future of my treatment.

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Christine H, UK
2001 - Multiple Sclerosis
October 2008 - LDN

I'm pleased to say I've been taking LDN for ten months, and am even starting to forget about the unpleasant symptoms I used to manage on a daily basis. Before LDN, never knowing what the day would be like was a real problem.

I'd always try to plan things in advance because just going to work on most days was the only thing I was able to do. By the time I got home, I'd be worn out. I often wondered back then just how much longer I could keep going to the office, but the thought of sitting at home day after day made me push on.

The disability caused by the MS in earlier years is what slows me down, and unfortunately, the LDN cannot cure that.

But I have my car and mobility scooter and I can get out and about and make commitments to do things now, which I would not have been able to do as easily before - especially on those days I used to wake up knowing it was going to be a bad day.

Another thing which has been helped by the LDN is my asthma. I've been on asthma medication since the age of 4, but around Christmas time, 2-3 months after starting LDN, I was able to stop taking my prescribed medication and have not looked back since.

I'm really glad LDN is part of my day now, because the benefit it gives to me is huge - not only for my MS but also my asthma - and it all started with a cutting from a newspaper that I was given to read.

When I read it, it sounded like something worth investigating further, so I went on the web to find out more. Whilst doing that I was very lucky to find Dr Bob Lawrence and contacted him by email. He sent back a very detailed list of all I needed to know.

After reading through it all I went to my local GP armed with all the paperwork. After discussing LDN with me, he was willing to let me try it.

That all happened last year around September-October. I didn't experience any of the early unpleasant symptoms I heard could happen, and my days are much more level. I wish I'd been told of LDN back when my MS started 8 years ago because the condition might not have taken a lot of my mobility away.

I for one am really grateful to Dr Lawrence for all his dedication in researching LDN and dietary requirements so people like myself can have a better standard of living with Multiple Sclerosis.

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Christine L, Ireland
September 2004 - Multiple Sclerosis
October 2005 - LDN

I was diagnosed with relapsing-remitting MS in September 2004 after experiencing two relapses within the course of 12 months. I experienced double vision and shaking and had to be put on steroids to get my bowels working.

My main symptoms were:

1. exhaustion and weakness
2. lack of concentration - I couldn't read anything longer than an article or very simple novel (5 years prior to my diagnosis I had qualified with a law degree so my ability to read had deteriorated quite rapidly during those 5 years)
3. when people were talking to me directly my brain very often couldn't absorb what they were saying and my eyes would start to roll in my head
4. Any sort of concentration at all would make my head and eyes hurt
5. I had recurring urinary tract infections (2 or 3 each year)
6. My eyesight was becoming increasingly blurred in my right eye
7. I was dropping things and bumping into things all the time

I started a course of LDN in October 2005 and felt immediate benefits. The only side-effect I felt from the LDN was vivid dreams for a couple of weeks or so and then these passed.

The improvement in my health has been so immense it is very difficult to remember all of the improvements but I shall try to list as many as possible.

No wait, it is probably easier just to mention the only remaining symptoms I have of MS and that is basically these 2:

- (1) I still suffer from tiredness and so probably will not work again but my energy level has increased enormously to the extent that I can get out and about every day now, whereas before I was lying either in bed or on the sofa all day, and;
- (2) I still suffer from mood swings.

Essentially those are the only 2 symptoms remaining.

I used to list the improvements in my health for my consultant neurologist to show how I was improving - so perhaps it is best if I just copy these out for you and update you with my latest improvements.

MS SYMPTOMS 24 MAY 2006

Improvement

- ◆ eyesight in right eye virtually normal
- ◆ tingling virtually gone - was tingling all over a lot
- ◆ improved concentration - within last 3 weeks was able to read a 'heavy' book as opposed to a novel
- ◆ appetite has returned - had lost appetite from Sept 2005 to Jan/Feb 2006
- ◆ agitation has improved - I can lie and doze during the day now (both steroids and LDN seemed to improve this symptom)

No change

- ◆ no improvement in fatigue or lack of energy
- ◆ have a lot of food intolerances - my diet has become very restricted
- ◆ worsening Symptoms
- ◆ pain in right arm from elbow down when lifting things, eg, cups of tea, teapots etc - this is more or less permanent
- ◆ when increasing dosage of LDN from 3mg to 4.5mg, I was in pain all over my body and had to reduce dosage back down to 3mg again

UPDATE -4 AUGUST 2008

Eventually I was able to tolerate 4.5mg and now I am on 6mg per day and have been for over a year.

- ◆ eyesight normal, except when under severe stress
- ◆ no urinary tract infections at all in 3 years - used to be on antibiotics 2-3 times a year before LDN
- ◆ tingling gone, except when under severe stress
- ◆ I can read with no problems whatsoever now, apart from tiredness, but concentration is excellent
- ◆ my appetite is back, with a vengeance, putting on weight rapidly
- ◆ I'm not agitated at all, although I can become impatient when very tired
- ◆ I still have food intolerances but these too are improving and I can eat many more foods now
- ◆ I'm physically and mentally stronger and more optimistic about life.

I can get out and about most days when before I was only able to get out maybe once or twice a week.

UPDATE 10 JULY 2009

Even during the past 12 months I can see more improvement both physically and in my mental well-being.

When I was first diagnosed with MS I could barely concentrate, however, I can now work a little from home. During the past few weeks I have type-set a book and prepared it for publishing, and that took about 4-5 hours work each day and required great concentration to proof-read etc.

Last week I travelled to Preston by car from Ireland to promote the book and was able to cope with quite intense physical and mental strain. I was able to talk to people for 4 hours during the book signing and not only did I not find it particularly difficult, I actually enjoyed it (which is miraculous). Before starting LDN I didn't enjoy anything because of constant tiredness and weakness.

My brother and his four young children came to live with my mother and I for a number of months. I was able to prepare our small house and help look after them - cook meals and collect them from school etc. This would have been absolutely impossible before starting LDN.

My quality of life has improved to such an extent I can say that I enjoy life again (not always of course because I get very frustrated at not being able to work).

I am so convinced about the efficacy of LDN that I tell practically everyone I meet that I have MS because most people know someone with MS and this gives me the opportunity to spread the good news of LDN. In fact I have become something of an LDN evangelist. I have helped persuade 5 people to start LDN and they are all finding great improvement in their health.

I am so grateful for all the work Linda and Dr Bob Lawrence in Wales do to raise awareness of LDN. I can say that it has changed my life beyond recognition both in large and small ways, and if I had my way everyone with MS would automatically be put on LDN.

18

Claire S, UK

1993 - Multiple Sclerosis

2005 to present, but with breaks due to cost - LDN

I have been taking LDN for 4 years, since 2005, and can confirm that there have definitely been improvements with regard progression of my multiple sclerosis.

After being diagnosed with MS in 1993 in my early teens, my condition began to progress slowly with occasional and partial remissions. My ability to walk began to degrade by the time I was around 15yrs old. I was still walking, but the distance I could walk was greatly reduced.

I was started on beta-interferon before I was 20, which may have slowed the condition but had extreme side effects, so much so that in the beginning of 2000 I decided that I would rather take my chances with the MS being untreated, despite how the condition was progressing.

By the age of 20, and after having suffered several falls, I was having to use a manual wheelchair, even in the house. By 23 yrs I was limited to only being able to stand up, and the only movement I could manage was shuffling a foot.

In 2005 I started LDN at 3mg capsules. I noticed the first beneficial effect within 20 minutes. My legs started to feel lighter and easier to move. The muscles felt more relaxed, rather than the usual feeling of rigor mortis setting in. I found it easier to get to sleep and woke up the next morning feeling refreshed rather than still tired. My energy began to steadily increase to a reasonable level.

Due to financial difficulty in reaching the prescribing doctor (in Reading) and the cost of the prescription, I had to stop taking LDN in late 2006. I soon noticed a decrease in my energy, my emotional state became depressed, and my legs felt like they were made of rock. I tried to obtain LDN from my GP, but they were unwilling to prescribe it, even privately, because they had not heard of it for this use or of its beneficial effects, etc.

So I had to find the money to return to Reading for the LDN prescription. I recommenced taking LDN at 3mg, but again I had to stop due to financial difficulties. I also had difficulty reaching the doctor. Again, my energy and strength decreased. My eyesight also deteriorated. I experienced optic neuritis and nystagmus, and this impacted my emotional state and I became depressed.

I thought I would have a last go at trying my GP (different from the first time as I'd moved elsewhere). To my joy, she agreed to prescribe the LDN privately at no cost for the prescription. I only have to pay the medication charge to the pharmacy.

My GP is now even trying to seek the LDN on the NHS. This has reduced the cost of treatment from approx £360 per month to £315 per month. My energy is returning, and I can stand up straight again now, which was very difficult due to every leg muscle being taut and tense.

The improvements I've noticed so far:

- ◆
- ◆ More energy and endurance
- ◆ Better dexterity
- ◆ Sleeping better (more refreshing)
- ◆ Skeletal muscles are looser with less cramping
- ◆ Eyesight beginning to improve (less flashing light or sun spots)
- ◆ Easier to stand (more leg strength)
- ◆ Slightly improved balance
- ◆ Clearer thinking (less brain fog)
- ◆ More cheerful and less argumentative (more relaxed)

The side effects I've noticed:

- ◆ Drowsiness, lasting maybe an hour after taking LDN (not to the point of sleep just very relaxed)
- ◆ Dry throat - I take the liquid version (drinking something stops it)

- ◆ Stomach - I get some digestive system twinges (but they're short lived, normal reactions of smooth muscle)

My progress, and the LDN benefits seem to get better each day with new things noted.

The benefits of LDN for MS need to be known to people.

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Colin T, UK

**17th April 2002 - Chronic Progressive Multiple Sclerosis
2005 - LDN**

I spent a long time trying to decide how to respond to your LDN awareness campaign.

I have been taking LDN for about four years now. A member at the therapy centre that I attend told me about it. Some years before, I started the Cari Loder treatment, which I am sure you're familiar with (b12, l-phenylalanine and lophepramine).

I had for months been plagued by what I can only describe as a combination of flu-like symptoms and hay fever which would come on over the morning and get progressively worse over the day. Having got to the desperate, try anything stage, I showed an article about the treatment to my doctor. He could have easily have put me off, but was in fact very encouraging about my trying it. The result was absolutely amazing and very quick.

Several years later the symptoms started again. It was at this point that I started the LDN and within a very short time the symptoms disappeared and have not come back. In short I have always felt very well during the time that I have taken LDN. Unfortunately, other symptoms of my Chronic Progressive MS have continued to get worse, particularly my hands and arms over the last month.

I am afraid this isn't very helpful to you. I am going to carry on taking LDN, but for me it hasn't stopped the progression of my disease.

Crystal N, USA

Nov 2004 - Secondary Progressive MS, and Transverse Myelitis
Sept 2005 - LDN

I am a 40+ year old mother of 3 kids. On November of 2004 I was diagnosed with Secondary Progressive Multiple Sclerosis and Transverse Myelitis.

At the time I had been working for a brochure company driving a van to hotels and other places putting in brochures in the racks to keep them full.

My first symptom was feeling extremely tired all the time. When I got home from work I would have to lie down and take a nap, which was unusual for me. Later, I read that tiredness is one of the first signs of MS. I then started having a lot of back and neck pain and then went numb from my feet up to my chest and could barely walk.

I visited our family doctor, and after explaining to him what was wrong he only asked for an x-ray and checked my lower back and of course he found nothing. So he quickly dismissed my symptoms to stress and too much physical activity. After months of this constant numbness and pain, I decided to go to a Chiropractor because I thought it was a pinched nerve. So I went and he did some x-rays and an MRI. The next day that doctor asked me to come in right away.

That 10 minute drive to his office was the longest drive filled with fear and anxiety I'd ever felt. When I arrived for my results he told me he could not examine my back or carry out any procedures on my back because there was a mass in my spinal cord from the lumber region to my shoulder blades but he could not tell me if it was a tumor or just a mass. He said he had made an appointment with a Neurologist for the next day.

The hours before the appointment with the Neurologist were the longest that myself and my family had to endure - at home, wondering what was in store for me and us.

The next morning at the Neurologist I explained the symptoms I was having. He did some more tests in his office, and asked for another MRI with and without contrast (important to diagnose MS), and admitted me to the hospital to do a Lumbar Puncture. He ordered three days of Steroids through IV in the hospital and another week at home.

A week later my Neurologist explained that after reviewing the symptoms I had complained about and reviewing my medical records he determined that I had Transverse Myelitis. Also, he knew I had Multiple Sclerosis before he got the results of the Lumbar puncture and that MS had been present at other points in my life. He just needed the Lumbar puncture results for confirmation.

When he told me I felt like I was in a bad dream. It felt like I hit a brick wall. My mind was numb and I didn't want to believe what I was hearing. I was so devastated and all I thought about was that I would end up being a cripple the rest of my life and would have to depend on others to take care of me. I was scared to death!!!

My husband and I sat my kids down and explained that I was sick. We tried to explain it in a way that they could understand for their age. They seemed to understand and didn't say much but I know they were worried. We also told them that I wouldn't be able to do a lot of stuff I was able to do before and they said they understood.

My Neurologist started my treatment right away, which is essential in treating MS. He prescribed Betaseron injections, a medication for MS which is suppose to help slow down the progression of MS but what the doctors don't tell you is that it's only supposed to help Relapsing Remitting MS (the 1st stage).

I was on Betaseron for the first 8 months after my diagnoses, but it wasn't helping me at all and just made me feel worse. I ended up getting a bad infection, called Cellulitis, in my right upper thigh from the injections. I was bedridden with Cellulitis for 3 months during the summer of 2005. I ended up having to have surgery to drain all the fluid. It was the most painful thing I have ever felt in my whole life. My husband had to help me up to the bathroom because I couldn't walk by myself and I cried all the way there and all the way back because of the pain.

In the next 8 months I went from using a walker to a wheelchair to a Hoveround power chair.

When I was bedridden with the infection I did a lot of research online and found out about another medication that some MS people were using, and it was helping them a lot.

I started e-mailing them and got all the information I could. The medication is called LDN (Low Dose Naltrexone) and it can be compounded into a capsule you take every night between 9pm and 3am. I went to my Neurologist and asked him about it, but he had never heard of it because it had not been approved yet for MS.

I printed a bunch of information about it and gave it to him and he said he would read through it and get back to me on it. A couple OF days later he called me and said it looked good and we could give it a try if I still wanted to. I said "yes", and he called it in. I started taking it on September 3rd, 2005. My understanding is that it can take up to a few months to get the full effect from LDN, but I started feeling effects from it the very first night.

LDN took away my MS Hug, and helped me walk without a walker, wheelchair, or Hoveround power chair. It also helped with some of my back pain, muscle spasms, most of the numbness or tingling in my legs, and my swallowing problems. Another benefit was that I was no longer fatigued most of the time. LDN gave me back the ability to do a lot of thing's I never thought I'd be able to do again.

It is difficult for people that don't have MS or Transverse Myelitis to understand what you are going through. This is a Neurological disorder and some of the symptoms cannot be seen on the surface. So others who do not understand what MS is may think there is nothing wrong with you.

After I was diagnosed with MS and TM I thought back to all my symptoms over the years and I can now link them to symptoms of these diseases. I was always misdiagnosed with something else or the Dr's would tell me it was all in my head. Believe me, I wish it had all been in my head.

After I was diagnosed with Secondary Progressive Multiple Sclerosis (SPMS) and TM, we went looking online to find information about MS and TM, but couldn't find any website that was comprehensive, so I decided instead of sitting around and pitying myself I'd start my own website. I gathered all of the websites I found about MS and TM and other information and posted it to make it easier for other people to find this information.

I started Crystal's MS, TM and LDN Website in 2005 and with that a monthly newsletter. I created an LDN Users Support Group for people that need support and information about LDN - for all autoimmune diseases and cancers, and I started Crystal's LDN Gift Shop.

May there be a miracle in YOUR life today and may you have the EYES to see it.

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Daisy Z, UK
1992 - Multiple Sclerosis
February 2005 - LDN

I first read about LDN at the end of summer 2004.

My body doesn't work well in the heat and I found myself looking on the internet for alternatives to the CRAB drugs my neurologist had been offering me for the past couple of years.

Although I fell within the NICE guidelines for being offered disease-modifying drugs I felt that the 'marginally better than placebo' benefits shown in the different drug companies' trial data didn't outweigh my symptoms at the time and didn't encourage me enough to start any of the NHS sanctioned treatments available.

I had been reading about the Swank and ARMS diets, theories on avoiding gluten and increasing poly-unsaturated fat intake so, after finding out about LDN on the internet I wanted to find out more. The more I found the better it sounded if only because it didn't require regularly injecting myself! I also preferred the idea of coaxing the body to treat itself better, rather than, as far as I could see, flooding the body with an inefficient set of pharmaceuticals - which utterly ignored what's not working in the first place.

The following month I started back at college as a mature student and picked up 'freshers flu' which would have been fine, almost a right of student passage except it appeared to trigger an MS attack where I didn't know which way was up and I couldn't stand or walk unaided. It seemed very unfair: My fellow students got this effect at the uni bar but were still able to stand up the next day! This subsided but has left its mark and flares up whenever I get overtired. For me, the disease modifying interferons seemed even more a wrong approach.

After visiting doctors on Linda Elsegood's list, I finally got a prescription for LDN. The medication was delivered from Florida shortly afterwards and I started treatment in

February 2005. I couldn't have gotten this far without all the phone calls Linda must have been making to doctors around the country to lay the groundwork for UK LDN availability.

The first month was fantastic, my mood lightened, I felt I had less 'brain fog' and everything seemed possible. I enjoyed the vivid dreaming. I hadn't been remembering dreams, vivid or otherwise, for years! I felt I had almost boundless energy and could walk the half mile to and from college twice a day.

I use a stick now, do regular Pilates exercises to a DVD in my front room and use an exercise bike at home, because I still lose my balance whenever I turn my head and that isn't a good feeling when cycling amongst traffic!

LDN hasn't stopped the disease dead in its tracks for me but I wonder where I'd be if I didn't have it. It seems a small price to pay for what could be doing me a lot of good. This is the hard bit about MS for me, not knowing for sure what might have happened anyway. When I take a day's break from LDN my bladder control worsens and I get fatigued more quickly but I have found when I take LDN continuously it loses effectiveness my muscles begin to ache and occasionally, spasm.

After listening to Dr Zagon's interview with Mary Bradley I'd really like there to be trial data on dosing that I could rely on rather than falling back onto trial and error with my own body.

I believe LDN has the potential to be a great treatment. I'm pretty sure It's made a difference over the past four and half years for me (as close to 100% certain as you can be with MS) but I wish there were further trials - not just on its efficacy or on whether to use it, but how best to use it.

David N, UK
1995 - Multiple Sclerosis
2006 - LDN

I first started having MS symptoms in 1995 when I was working in London.

My walking became awkward, and I tripped over in the roadway. At first I did nothing about it, but when it continued, I decided to get it checked out. I went into the National hospital for tests and was diagnosed with MS.

I was able to continue working until 2003 when I was forced to give up.

I knew about LDN for a long time before I decided to take it. The sheer thought of taking tablets that I'd never heard of, or the possibility of unknown side effects was not something that filled me with glee.

Then again, what did I have to lose? Absolutely nothing. So, in 2006 I plucked up the courage to take LDN, and within a few days I noticed I had more energy.

When I experienced Trigeminal Neuralgia, a horrible mouth pain that required pain medication, I had to stop LDN for a while. My MS became worse up until the day I went back on the LDN.

LDN is not some sort of miracle cure. My MS didn't disappear. I still get my off days, but with LDN, the good days vastly outweigh the bad.

Since starting on LDN in 2006 my energy has been fantastic and my quality of life is so much better, and who knows, one day....

I take one 3mg capsule each night before bed, and for the moment that dose is fine for me. I get the LDN as compounded capsules from Dickson's Pharmacy in Scotland and would recommend them to anyone.

I had nothing to lose, everything to gain, and I now have a life.

To anyone undecided about LDN, I say 'give it a try'.

Don't expect miracles. See what happens. If you don't try to help yourself, then no one will help you. Be positive and go for it. Good luck!

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Davinia W, UK
DATE - Multiple Sclerosis
July 2008 - LDN

I found out about LDN on my own.

I was searching online seeking some sort of treatment for my MS, because I don't think MS sufferers get any help at all.

I found Linda Elsegood's story during my search, and I was amazed. I was also determined to start this drug, and I had nothing to lose.

Since taking it, I have more energy, and don't seem to be as forgetful as before.

I think LDN should be available to everyone on the NHS. I buy my own, yet my friend gets hers from the NHS because her Neuro agrees to it, whilst mine refuses to let me try it. Like many others I had to get it myself privately and I will stick by it now. It really is time to have this choice.

24

Deanna V, USA
October 2003 – Relapsing Remitting Multiple Sclerosis (RRMS)
July 2005 - LDN

My first symptoms were leg weakness, tingling, buzzing, urinary urgency, and L'hermitte's sign.

I was in my nursing clinical when symptoms began. After my MS diagnosis, I quit nursing school.

From the onset of symptoms in July 2003 until August 2005, the only medicine I took for MS was Copaxone, with occasional IV Solumedrol treatments. During this period, I suffered with severe fatigue as well as the onset of new symptoms: Mild numbness began over about 50% of my body. It occurred in my limbs and in various areas all over.

Scans indicated my MS was mostly in my spinal cord, so a lot of my symptoms occurred over both sides of my body... both legs, both arms, both hips. I also had bladder urgency, and the fatigue was crippling.

I went looking for alternative treatment. I did some web searches and came across LDN. I remember one woman named Joyce told me about it and how to get it. I took all the info to my Neurologist, and I basically told him, "I am going to try this". He smirked, as if thinking it was a bunch of bunk, and prescribed it for me.

That was in the Summer of 2005. From the moment I took it, I felt a difference. The fatigue diminished the very first day, and it continued to get better every day after that. Even the numbness eased. I then went back to work a few months later and have been working ever since.

It is now almost 4 years since starting on LDN, and I still work full time.

I guess what I'm really trying to say is... Here I am, 6 years after my MS diagnosis, and I am still up and running. I walk 3.5 miles a day, do aerobics for 30 minutes straight, and I lift weights.

I don't even look like I have MS. Is it the LDN??? All I can think of is... what if? What if I never took LDN? What would I be like today?

Oh, and I also have a sister with MS who refuses to consider LDN. She uses a cane and a wheelchair.

25

Deidre A, Hong Kong
October 2005 - Cervical Cancer (Adenosquamous Carcinomas)
February 2007 - LDN

I am a LDN user of 2.5 years.

I was diagnosed with cervical cancer of the type Adenosquamous Carcinomas, the rarest form, which has features of both squamous cell carcinomas and adenocarcinomas. I underwent Wertheim's total hysterectomy and right salpingo-oophorectomy (removal of right fallopian tube and ovary).

After surgery, reassessment found 'Poorly differentiated Adenosquamous Cell Carcinoma, at least 4 cm in maximum extent with prominent lymphatic permeation, 3 positive Lymph nodes - Comment pT2N1Mx (*TNM System Cancer Assessment).'

I began concomitant External Beam Radiotherapy (RT) with Cisplatin chemotherapy treatment. This involved 29 RT treatments over a period of 5 weeks, 5 cycles of Cisplatin (one each week for 5 weeks). I completed the treatment on 9 January 2006. During treatment I experienced the following side effects: fatigue, severe cystitis, severe pain on bowel movements.

Conventional radiation and chemotherapy treatments following surgery, from October 2005 through 2006, but didn't halt the growth or spread of the cancer.

In January 2007 a follow-up PET scan (2) identified nodules in my lungs suspected as metastatic cervical cancer, and confirmed as metastases with at least 13 nodules, the largest nodule (3) being 1.3 cm. Reclassified cancer to Metastatic Stage IVB (based on TNM System Cancer Assessment).

By Feb 5th 2007, my cancer had progressed to Metastatic Stage IVB, with multiple lung mets. My cancerous nodules were doubling in size every 33 days. All conventional therapies had been exhausted.

As a prognosis, I was given 10 months to live and told to get my affairs in order. I was offered palliative chemotherapy, but I declined.

Then I found out about Dr Bernard Bihari and LDN.

I got my first LDN prescription for 4.5mg on Feb 12th 2007. I began taking it between 10pm and 11pm each night.

In the first year, new tumors were detected, but nodule growth of old tumors had slowed dramatically, with the doubling rate reduced from 33 days to 212 days.

In June 2008 I underwent Radio Frequency Ablation (RFA) to destroy the largest nodule in my left lobe, hoping to reset the 'clock' on the largest tumor growth, expecting that the LDN would continue to hold down the growth of the other existing nodules, and extend my high quality of life.

The treatment with RFA to one of the larger tumors in my Left upper lobe was successful. A subsequent scan revealed multiple metastatic nodules but some were now showing calcifications.

My last treatment was surgery in Feb/Mar 2009 to correct pelvic radiation damage caused by the External Beam Radiotherapy (RT) in Dec 2005/Jan 2006. After that surgery I spent 4-5 months healing and didn't go in for any more scans.

Doctors have continued to classify me as terminal, but I'm still feeling well after 2.5 years on LDN, and I'm still here - 28 months later, and 18 months past the most optimistic 10 months I was given.

Apart from early on, LDN has had no side effects for me, and anyone seeing me would never believe I have cancer since I feel and appear healthy.

Dianne W, Australia

Oct 1986 – Relapsing Remitting MS (RRMS)

2003 - Secondary Progressive MS (SPMS)

January 2008 - LDN

I was diagnosed with MS in 1986. I chose not to take any of the 'usual' MS drugs and started on the Swank diet in 2005. I became SPMS in 2003 when walking deteriorated (weakness with limp and spasticity) plus sensory symptoms buzzing, tingling, jumping skin etc.

By 2007 I began having bladder problems (nocturia) and urge incontinence.

I started LDN in January 2008 at 3mg, then later increased dose to 4.5mg. I did have some problems with increased symptoms and lowered my dosage back down to 3mg. However, after dealing with stress, illness etc. went back up to 4.5mg, which I have now been on for over 12 months.

My main improvement has been with bladder function - now normal again, and sensory symptoms are now almost non-existent.

Walking is still affected and weakness in right arm is also evident at times but I believe this has been caused by 'old damage', which may be permanent.

Occasionally, I get return of some symptoms but these can be attributed to stress, over tiredness, or illness and usually resolve after a short time of rest etc.

I very much believe in LDN and will never stop taking it.

It is very frustrating that trials to prove its efficacy are not being done.

I am sure this is because the drug companies 'don't want to know' and it would affect their profits significantly.

I am trying to spread the word as much as I can here in Australia and more people are aware but many are still not and LDN needs to be recognised as a viable treatment for MS.

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Eileen P, Ireland
DATE – Multiple Sclerosis
July 2004 - LDN

I've been taking LDN for 5yrs now.

Prior to starting LDN, I used a walking stick from time to time because my legs and arms were so very heavy. I had no motivation as fatigue would take over.

The heavy-ness in my legs went after starting LDN, but for a while, I felt like I was slightly worse and wondered if I should stop. Around the same time, I was attending an Occupational Therapist for Shiatsu. They told me I had more tone in my limbs, and that helped me to decide to continue with LDN.

It's now 5yrs later. I work part-time. My energy levels are high, and I am flying it without any aids.

I have no hesitation in recommending LDN to anyone with Multiple Sclerosis. I know it is cheap and profitable, but I cannot understand the reason why any neurologist who cares about his patients does not prescribe it.

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EF, UK
2002 – Primary Progressive Multiple Sclerosis (PPMS)
2007 - LDN

I am a 48year old man who has been diagnosed with PPMS since 2002 - although I suspect I had it several years before that because the symptoms and signs were around before that.

I have been taking LDN for around 12months after being told about it from a friend of a friend. It has helped my fatigue, bladder and hopefully, is stopping the progression of M.S.

I wish I'd known about it before.

Another positive effect of LDN that I didn't expect is that it has helped my erectile dysfunction, which is bonus.

The negative side of taking LDN is the cost. Although the drug itself is cheap I have to get a private prescription for it. This costs me a lot to see the private consultant and

then I pay for a month's supply of pills on top. Due to my tremor I cannot administer the liquid form of LDN, which would halve the cost.

I am about to be medically retired from work and money will be tight in the future.

I resent paying such a high price for the prescription but feel that it is making a difference to my life.

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Elise P, Panama **September 2002 - Multiple Sclerosis** **June 2004 - LDN**

I am presently living in Panama. We moved here in 2005, following a sunshine hunch that was not yet substantiated by research at the time!

I have two boys, and they were 14 and 6 at that time. I have a family history of MS.

My experience is eerily similar to what my maternal grandmother experienced. No one remembers any relapses, just a steady relentless decline. I only knew her in a wheelchair. Her right side was affected, but with me, it's my left side.

I was diagnosed with the infamous 'white spots' in September 2002. I had a bout with optic neuritis in December of 1997 but MS wasn't even mentioned as a possibility at that time, unfortunately. I have been primarily researching and managing my own care and LDN was one of the first exciting things that I came across. I am trying to confirm the actual date that I started but the prescribing doctor is in the US and this is a holiday weekend, so I couldn't get a response. I think it was Spring 2003 or 2004, so I'll go with the later date for now. I'll let you know the exact date when I get confirmation. I started on a 3.5mg dose, then moved up to 4.5mg.

I started following the Best Bet diet in February 2009. I fought having to give up eating things I loved as long as possible! I chose the Best Bet diet as it was the most different from my normal diet and I figured my normal diet had gotten me where I was. It seems all of the MS diets have low saturated fats in common but differ on dairy, gluten, meats and legumes. I think these could possibly be explained by food intolerances. Not being able to afford fancy testing, I chose the most different.

I don't have a fantastic success story... I hope I'm deteriorating slower but I think that is the same with those on the crabs... in fact, I've read those 'wonderful' accounts of women 'stabbing the monster' to fight this thing and as the book goes on, they discuss incontinence pads and catheters and scooters versus wheelchairs... I read a lot of books standing in Borders... and I read very fast!

I realized that I wasn't reading about people beating this, they just felt like they were doing something. From a placebo standpoint, a painful injection is very powerful, right behind funky colored pills... they both work way better than plain white tablets!

Right now, with LDN, 4AP, and vitamin D, I'm sleeping through the night, mentally alert and rarely napping so that is all good! I just wish I could find the answer to mobility for me. My foot drop and muscle weakness is still quite a problem. But, I can definitely notice the difference if I stop any of those three! I do take other supplements but there isn't an obvious effect with them. I stopped the LDN for two weeks last year and I was up multiple times every night to use the bathroom and perhaps, as a consequence, much more tired all day. I will stay on LDN... I have learned my lesson!

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Ellen D, USA
18 May 1994 – Multiple Sclerosis
January 2009 - LDN

My story begins Christmas Day 1989 with the birth of my third son.

It was a normal pregnancy as I went jogging into my fifth month. I actually remember running with my tape headset playing, Christopher Cross song, 'Ride Like the Wind', feeling like I could run faster listening to the music.

I felt great nearing 40. My family was healthy and I was working part-time as a Registered Nurse with the plan of taking a few months off before heading back to a job with more responsibilities. I had decided this would be the last day of running until after the baby arrived. Little did I know I would never run again. My son arrived in a very easy birth. No pain! How strange when he was 8.5 pounds. Years later I understood why.

After a couple of weeks, I noticed my legs felt very heavy and I was slow getting around. My body didn't feel right. I went to my doctor and requested an MRI of my brain.

Lo and behold, on July 4th, 1990, it was very hot and humid. My husband and my two older children, 10 years and under, were walking in the village parade and I was pushing the baby in the stroller. I thought of collapsing on the cement. Maybe I was having a stroke!

My doctor had called the night before warning me of possible problems with hot weather after reviewing my initial MRI finding 5 lesions on my brain. My husband ran home to get the car. I could not walk any further. Whatever it was, my plan was to stay in denial. I was a psychiatric nurse at a hospital and talked often about denial with family members on the young adult unit, and now this is what I wanted. Total denial of any physical body problem!

August 1990 was my first appointment with a Neurologist. He told me a possible diagnosis was multiple sclerosis. I asked myself, what is that? Despite twenty years of nursing, I had never taken care of anyone with multiple sclerosis!

The doctor had no information for me. I could probably find something at the library. My husband and I left his office stunned and vowed never to return. I stayed busy at home with family and my body appeared somewhat stable so I didn't investigate until walking became a problem.

1992: My first adventure to solve the problem: An appointment with my M.D. Diagnosis was made with Hair Analysis. His clientele was 90% cancer patients, though he did accept other illnesses. He put me on a specific diet all according to my hair samples. I was fascinated with his unconventional program. He told me right away I would be on organic meat, root vegetables, grains, daily carrot juicing and yes, twice a day coffee enemas. Organic coffee, of course! Coffee enemas were essential for detoxification of the body.

The program also consisted of about 70 daily supplements, enzymes and other modalities that kept me focused. It was good for me and kept me grounded. I did this program for about two years. I had been a vegetarian for long periods of time in my twenties but this diet gave me more strength and balance.

I had returned to my nursing job with a new title as the head nurse of the young adult, unit with around 30 beds. My life was busy. I had a promotion at work and was determined to stick with it knowing all about stress. That job lasted nine months and I stepped down to part-time.

I had taken six-month leaves several times through my nursing years after my diagnosis, so I could regroup and stay healthy. I was lucky to have my job as long as I did.

My career came to a screeching halt in 2001 when my unit dissolved and I was asked to work at the city jail. I did not need more stress. I retired from my nursing career as I was getting weaker and knew it was unhealthy for me.

My husband and I are trained massage therapists. Naturally, it is a joy to give and receive massages. It has been several years now that I cannot participate in exchanging a deep massage. It is not easy to continually let go of your power. I was a follower of transcendental meditation since the 70's, although I wasn't dedicated to a daily practice. It has now been more important for me to stay committed everyday to meditation.

In mid July 1994, I was hospitalised for weakness and had difficulty walking. It was a five-day inpatient hospital stay, with 1 gram daily IV of Solu-Medrol. I then started on daily shots of Copaxone for ten years. I tried all the CRAB drugs at some point, but mostly used Copaxone.

Western medicine had entered my life and I decided to try anything to keep these symptoms at bay. I truly believed I could cure myself. I questioned my doctor many times about the effectiveness of Copaxone as my symptoms continued to get worse. I was upset when my penmanship was almost unreadable. This was not good.

I continued to walk, but now with a cane. Steroids were my only hope, because I always had some relief with my symptoms. I continued once a month with IV Solu-Medrol, but at the same time this was unhealthy for my bones. I had tried plasmapheresis in 1999 with little improvement. I bought a wheelchair, but fought that

concept kicking and screaming. Just ask my husband. He has been my partner, always patient and loving through this challenge we share together.

This past year I had accepted defeat, because fatigue had set in and I was so tired of the fight. I love my family, but I was leaning towards depression thinking negative thoughts.

In January of 2009, my dear friend and old boss informed me of a drug called LDN. I thought, 'what the heck', investigate the medication. After research and calls to Dr. Bihari's office in NYC, I decided to start LDN at 4.5mg on January 19, 2009.

I discussed using IV Solu-Medrol with Dr. Bihari's assistant on the phone. I was on 1gm, IV Solu-Medrol, once a month and wanted to get off of this drug. He advised me to start the LDN and slowly titrate down the steroid. This is the plan!

I have decreased my steroid to one half gram every 6 weeks. The only side effect for me on the LDN is insomnia. I have taken Ambien, a sleep sedative and plan on discontinuing it soon, although it's been very helpful for my insomnia.

Feb 8, 2009, I stopped daily injections of Copaxone.

Feb 24, 2009, I stopped nightly Ibuprofen 400 mg. I believed it helped me with inflammation over the years but now take DL Phenylalanine. As of right now, I'm not sure how this works for me.

Since my diagnosis I have had multiple acupuncture treatments and have always found this experience a healing.

I see the chiropractor 3x a week for adjustments. I have done physical therapy this past year and that has been very helpful in understanding body mechanics and the importance of walking correctly. I feel like I'm starting over.

It has been 19 years of learning about disability and how to continually honor the experience. I forgot to tell you that I'm still walking and my cane has become a real need. I am fortunate to drive my car so I'm grateful for things we all take for granted.

My husband has noticed my improved mood and positive energy change immediately since the start of LDN. I am back to my upbeat self. I feel good and I'm noticing little changes, all positive, while on the LDN.

My penmanship has improved 90%. I'm devoted now to optimism and my new regimen. I know my positive attitude will help me with the on-going challenge.

The past two years I have incorporated yoga, (Rodney Yee DVD) into my daily workout and feel that it keeps me centered and aware of my body alignment. I also swim laps in the summer months.

I continue with the supplements: multivitamin, vitamin C, D, E, fish oils, Probiotics, DL Phenylalanine, Calcium with Enzymes. I have also taken Bio-identicals for the past 4 yrs. I can't forget Fosamax with all those years of steroids. I did get a bone scan last month that indicated my bones had improved since 3 years ago. That was good news.

If you are thinking of trying LDN, journaling is a valuable tool to recall past events. All of

us make significant decisions for our health and our body/mind needs time to adjust. Journaling has helped me capture those moments of time.

I'm a little frustrated right now with some recent setbacks, probably due to the weather being so cold and so highly changeable. I was going to end steroids in July, but I'm now considering a longer and gentler path because I've been on them for so long. I'm getting professional advice and trusting my instincts on the best approach and timing.

I have been on LDN for two months and look forward to everyday with the hope of continual improvements with my health. Thank you for this opportunity to share my thoughts with you.

Update - 19 May 2009: I went to see my neurologist today and had my 250mg IV steroid, titrating down, probably finishing in 2 months, July 2009 as planned. Everything else is ok. My doctor actually said good things about LDN and said it looks hopeful as a new treatment!!

I received my news of my MRI taken in April. Everything is unchanged since last MRI. No Active demyelination. Stable. I'll take that and continue with my plan. I went to a MS dinner last week and met an engineer that feels vitamin D does not get into your system unless it's a gel-cap. Tablets don't digest. He also said liquid fish oil is the best. I'm off to the vitamin store to research and will update later.

Emily J, USA
August 1991 – Multiple Sclerosis
2004 - Breast Cancer Stage IV
May 2005 – Primary Progressive Multiple Sclerosis (PPMS)
April 2006 - LDN

I was first diagnosed with Multiple Sclerosis in August 1991.

In 2004 I was diagnosed with Stage 4 Breast Cancer that had metastasised to the lymph nodes. My treatment consisted of a mastectomy, chemotherapy and radiation therapy.

Then in May 2005, after almost 14 years of slow MS progression, my diagnosis was changed to Primary Progressive Multiple Sclerosis (PPMS).

I had to use a cane to walk and was so exhausted I could only shop for around 30 to 45 minutes at a time. This meant I only shopped for a few things at a time. Walking was terribly painful due to osteoarthritis and osteopenia, the first stage of osteoporosis. I could not stand up long enough to cook supper or even to clean my house in an afternoon. Life for me was slowly closing in and I felt as if I could not put my family through this pain.

In 2006 I heard about Low Dose Naltrexone (LDN) as a treatment for my MS. I joined the Yahoo LDN chat group to learn more, and in April 2006 I began taking 3mg every night. It's been almost 2 years now and I can tell you my physician is thrilled with the results.

I started taking 3.0mg Naltrexone in Apr 2006, but in January 2008 after nearly 2 years, I increased my dosage to 4.0mg. I cannot tell you how wonderful it has been to know I'm responding to this drug, especially as I'm well over 50 years old.

After commencing LDN my MS symptoms did not increase. If anything, some of them decreased. It was not an overnight miracle either. As the months, at least 4 or 5, went by I really did not notice any marked decrease in my symptom. It was so subtle I adjusted without noticing - but my family did.

I began to stand for longer periods. I was not using the cane nearly as much. I planted flowers and worked at weeding the garden. My husband brought it to my attention that my housecleaning seemed to be improving. (I hate housework so I schedule it on Saturdays and if I can't do it on Saturday it just does not get done.)

My shopping trips went from minutes to hours. I'd began to shop for longer periods, without carts, at the department store and I'd begun doing more of the types of activities I used to do without thinking before I had MS, but was constantly challenged by after I developed MS.

The improvement was so very gradual I reached a point where I forgot about my MS limitations and pushed myself a bit more into doing things. As I exercised more I got stronger. This could be the key to those folks who may expect LDN to right their symptoms. I pushed because I wanted my abilities back. I would walk farther and not let feeling sorry for myself get the better of me, and LDN (gradually) allowed me to do that.

There have been other benefits as well. Before LDN I was taking 1.25mg thyroid medication (Synthroid), but within 3 months of commencing LDN my doctor noticed my levels were too high. I began reducing the dose and as at February 2008, the dose had reduced 40%, down to .75mg Synthroid daily.

I also gave all the LDN information to my Oncologist who is one of the top men in his field and he too is interested in the effects of LDN.

So far I am cancer free and my MS is at bay. LDN is not a cure. I still have my good days and my bad days but I do feel that my bad days are less since I have been on LDN. I am ambulatory and I no longer need my cane.

Here's a hint for those of you thinking of going to your family doctor: Take all of the information from the LDN website which describes LDN, and ask him/her to read it. The rule of thumb is - 'he who speaks first loses' - so if he reads it in front of you don't say anything until he's finished. If he states he will read it later then tell him you will set up an appointment to go over the information with him. (They get too busy and it ends up in the round file.)

When I took the LDN information to my family doctor he was intrigued, then after a long silence he said, "Let's do this" – and he is amazed at the results. I wish everyone could have the kind of doctors I do. My family doctor is fresh out of Medical school and is willing to listen to patients.

My Oncologist is tops in the field and even he is looking more closely at LDN. Same scenario, I gave him the literature and asked him to review it. He is a very busy man but on my next appointment 4 months later he was so amazed with how I was doing he said he was going to go back and revisit the information for some of his other patients.

I'm still taking 10mg Baclofen three times a day to relax my muscles. I continue to take Arimidex (for estrogen positive cancer as it has to be taken for 5 years, and I take Amantadine to counter extreme drowsiness. Also, my oncologist has me on a cancer regime of eating more fruits and vegetables (minimum 5-6 servings a day).

Thanks to the LDN website and Yahoo group I'm on a lower Synthroid dosage and I have lost almost 40lbs since improving my diet. My symptoms haven't increased - some have decreased, and I hope yours will too.

Update - July 2008: I still take LDN and am still benefiting in the same way from LDN. No changes to report.

Update - July 2009: I am doing well. I have a lot more stress in my life these days but still on two feet.

We lost a house in the Flood in Iowa. We were not in the 'Flood Zone', so no flood insurance. It was totalled. My daughter was living there and she is still homeless, and we are still trying to get a settlement since we are not entitled to Fema help.

We are now in line for a buyout but they are telling us a minimum of 18 months before they begin. Meanwhile we have to mow weekly and shovel the snow when it snows. We live 50 miles away and it is just a pain - let alone we had to clean the place out and check on it weekly because of squatters.

But enough of that... I am seeing a little progression of the MS, but if I take time to rest it seems to abate. I'm working full time and doing well at that. There's nothing else to report. I am still taking all medications and the 4 mg of LDN. Oh, and no cancer has returned. Now 5 years free. Will let you know of anything else new.

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Fabienne B, UK
February 2004 – Multiple Sclerosis
11 June 2009 - LDN

I have been taking LDN since 11th June 2009.

I started at 1mg and I immediately started sleeping better.

Increasingly, I also have improved bladder control. I am now taking 2.5mg as I found 3mg too much. It made me too sleepy and I found it harder to get going in the morning.

After just one month I am very happy and hope to benefit further. Overall, my mobility has been up and down. I have experienced better days but not a sustained improvement yet.

I am in contact with Doctor Bob Lawrence who advises me on nutrition as well. Luckily, I was already following an appropriate regime and have only had to increase my fish oil and zinc intake.

This opportunity to take LDN has given me a boost and much hope.

I hope to be able to report more improvements soon.

Francie S, USA
Sept 2000 - Multiple Sclerosis
Mar to May 2009 – LDN

I was diagnosed with MS in September 2000, when Texas had nearly a week of 100+ temperatures. I had no idea that it was partly the heat that was so debilitating, but it finally landed me in the hospital, where I spent an extra day after the IV prednisone because the temperature was still 112 degrees outside.

My neurologist gave me the choice of which ABC drug to go on, and was pleased when I chose Copaxone as the least destructive to my immune system. I religiously took a Copaxone shot every day for nearly 9 years. I swear that I probably did not miss 10 shots in that entire nine years.

Being over 50 at diagnosis, I felt lucky not to progress rapidly during that time. But, the accumulated disabilities did start to add up. My left leg would occasionally give out totally and even when it was good, there was marked weakness. The fatigue was tangible as only an MS patient would understand, and the heat would put me in bed for days at a time.

Worst of all was the mental fog. In my younger days, I had a photographic memory, but I lost entire years from my memory bank because the short term memories did not get stored into the long term vault.

Then in the spring of 2009, the unthinkable happened -- along with my job, I lost my employer provided health insurance. There was no way that I could afford the \$1,600 per month to continue the Copaxone. Even the \$600 per month insurance payments would have put us in the poor house.

I had no alternative but to do some research on my own and see if there were something else out there that would make a difference in my life.

I am so GRATEFUL that I found LDN, a protocol using Low Dose Naltrexone that helps the immune system, and has put my symptoms in remission.

I can't adequately find the words to express the difference LDN has made in my life. I'm now over 60, and after being on LDN for only a couple of months, I have just returned from a trip to the Colorado Rockies where we took two of our horses and rode for 2 hours a day for over a week. I climbed mountains and breathed the thin, clean air with a renewed joy of life that I feared would never be a part of me again.

My husband is pleased to have his wife of over 40 years back by his side and my mother cried when she saw me on my feet with a grin on my face and a twinkle in my eye, not bent over struggling with each step that I took.

I am still somewhat atrophied from years of not being able to use my body the way I wanted, but the muscles are coming back almost as quickly as the memory. The mental fog is rapidly lifting, and I can now remember a phone number after dialling it once.

It has not made a big difference to the heat sensitivity problem, but I will learn to live with that. What it has helped greatly with is no more fatigue. I sleep like a baby through the night, and my cognitive function is vastly improved. My left leg and right arm are no longer nearly useless, and about as normal as they were as a youth.

I guess the thrill is just how 'normal' I feel. I will never go without my LDN.

My hope is that the MS Society will spend some of their massive research dollars on this cheap generic drug that is showing so much promise for thousands of MS sufferers, and that has no side effects.

I realize that the ABCR drugs help support the Multiple Sclerosis Society, but the Society is there to serve us, the MS patients - even if it means that the thousands that we all spend on expensive and scary drugs is cut way down by the use of this generic therapy that is cheap, safe and easy to administer either orally or topically with a cream that you just rub in.

I cannot thank my lucky stars enough that I lost my health insurance and found Low Dose Naltrexone.

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Hannah G, UK

**1997 - Secondary Progressive Multiple Sclerosis
2006 - LDN**

I've got Secondary Progressive MS. My MS started about 15 years ago but wasn't diagnosed until 1997. I am in my mid forties and am married. My husband and I were disinclined to start a family, particularly because after leaving college, I was showing the first and most frightening initial symptoms of MS.

Having always been healthy, I thought, wrongly, that I would recover entirely after suffering 4 episodes. I also suffered a short period of colour blindness for which I chose not to seek medical help.

I later suffered two 'petit mal' fits within 10 days of each other. Because of the fits I was given an M.R.I. scan and was treated with the drug Epilim. Fortunately the doctor who dealt with me was careful to make sure that the treatment didn't last longer than 6 months, as he had experience of epilepsy patients for whom the dose of Epilim continually went up. Great handfuls of my hair had come out already as a result of taking Epilim.

I first heard about LDN from a feature in New Pathways.

At around this time, my husband was doggedly tapping away on our laptop trying to discover if putting in 'LDN' and 'Scotland' might turn up any supplier within this country.

I ordered a Fact Pack from the MSRC and was glad to be able to place an initial prescription for a one-month supply of LDN at 3.5mg strength. I found the first order too expensive, so I placed my second order through an internet supplier. Following that, I placed orders through Dickson Chemist in Glasgow.

Since starting on LDN, I've been provided with private prescriptions from three different GPs at my local health practice. They were interested in the idea that I, as a patient, could present them with details of something they'd never come across before and a request a private prescription in order that I could get it!

The most noticeable immediate benefit for me was that I no longer had horrible reactions to heat. I remember how totally unbearable heat used to be before I started on LDN.

I wish taking LDN would help me walk! I'm taking 4.5ml of LDN on a regime of 10 days on, 2 days off, and have just learned that most take LDN every day without a break. I'm intrigued by that. I walk with two sticks, I take baclofen in tablet form when needed, and I take 10mg tamazepam nightly for sleep.

I have to stop and remind myself how dreadful I used to feel before I began taking LDN. LDN allowed me to feel a lot sharper mentally within the first month of taking it. Things used to be particularly unbearable in hot weather. I still find hot weather difficult, but far more tolerable with LDN.

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Helen O, USA

**February 1999 - Chronic Fatigue Syndrome, Myalgic Encephalomyelitis
Feb 2009 – LDN**

I started taking LDN about 6 months ago for CFS/ME. I had been under Dr Gilhooly's care since October 2008, and had made good progress on nutritional supplements, mainly high doses of omega 3, which I found reduced my pain levels a great deal.

Despite the improvements, in Jan 09 I was still having setbacks, or crashes, causing dreadful mental and physical fatigue, muscle spasms and twitching, lymphatic pain, all of which resulted in me being able to do very little, requiring help to even look after the children.

I started on 1ml LDN daily and over the last few months I have managed to get up to 3.5ml. I'm taking it slowly as I had a strange reaction when I went from 2ml to 3ml (my head felt as if everything was going slow around me).

The big question is, has it helped me? Yes, the first thing I noticed going was the muscle spasms and twitching. This stopped within a few days of starting LDN.

Gradually, over the last couple of months, I've noticed an increase in my energy levels... my brain fog is so much better... I remember my words now... and, in fact, I remember so much that my friends and family now struggle to keep up with me... which I find very amusing.

I can now walk over 2 miles at a time... and have not had any major crashes since getting the dose up to 3ml. I am hopeful of getting up to 4.5ml in the near future.

Exactly one year ago I was very ill. I was losing weight and in considerable pain every day, with no real energy. LDN has given me and my family hope, and I would very much like to help raise awareness in any way I can.

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Huw E, UK
2004 - Primary Progressive Multiple Sclerosis
April 2009 - LDN

I was diagnosed with primary progressive MS in 2004.

This was the result of more than two years of investigation. Following diagnosis I was supported by an MS Team based in Cardiff. Their help, whilst appreciated, has been confined to 'approved' medical options which, in my case, consisted mainly of neuropathic pain blockers and physiotherapy.

Clearly the exercise involved in the 'physio' activity was helpful, however, the medication was less successful and resulted in very little pain relief and an adverse side effect of, what I can only describe as, a 'brain dead existence'.

In the early part of this year I was made aware of the use of LDN in cases of MS. I approached my local GP for the provision of a prescription. The initial reaction was very positive, the prescription was provided and, with great efficiency, Dickson's Chemist in Glasgow provided me with the liquid form of LDN.

At this stage, I feel the need to stress the importance of increasing the dosage levels gradually until the maximum recommended level is reached.

At the end of the third week of treatment I began to feel the senses in my feet for the first time in a very long time. This was accompanied by a better sleep pattern resulting from reduced muscle anguish in my legs. At this stage, you can imagine the optimism that was beginning to build up. However, it was short lived, because my attempt to procure a repeat prescription from my GP was refused.

There was no real explanation from my doctor other than to say that contact had been made with my local MS consultant. I can only assume that their conversation had 'reflected' on the non-approved status of LDN in the treatment of MS. This change of circumstance resulted in my continued use of LDN being disrupted until I was able to set up a source for private prescription. This was achieved through information obtained through LDN Research Trust.

I have now completed four months of continuous LDN medication and make the following comments:

- ◆ Noticeable improvement in sleep pattern (I have dispensed with the need for diazepam and baclofen to help with sleep and muscle relaxation).
- ◆ An improvement in the burning and anguished sensation in both my feet and legs.
- ◆ A very substantial improvement in mental alertness and 'feeling of well being'.
- ◆ The mental fatigue previously experienced has diminished to the extent that people who are close to me have commented on the difference.
- ◆ A flow-on effect from improved well-being has been a heightened sense of 'feeling positive', which naturally, leads to every day activities being much more pleasurable. I only wish there could be a more scientific way of measuring the level of improvement in order to convince would-be sceptics of this alternative approach to the condition.
- ◆ On the slightly negative side, I did experience a bit of a relapse when I reached the maximum level of 4.5mg LDN, however, at this juncture I am not sure whether this situation was influenced by an infection that I have recently been treated for. At this moment, I have reduced the dosage of LDN back down to 3mg without adverse effect.

In conclusion, it would be ridiculous to suggest that I could walk (or run) a marathon, but... the desire to tackle every day chores is approached with more optimism, even if it is achieved a little at a time.

I hope my comments will be of help to others.

Janet T, UK
1986 - Multiple Sclerosis
May 2004 - LDN

Six years ago, when we moved from the London area, I'd just had a two-week stay in a hospital because of a serious back problem. This resulted in me being on a concoction of drugs including very high dose morphine, which was certainly turning me into a zombie and probably was killing me. I had rejected the option of having my spine cut chemically. None of the drug treatments dealt in any meaningful way with the severe back pain resulting from the interaction of MS spasms with the separate back problem.

A local GP helped me to wean off the prescribed drugs and achieve some improvement with one of the now infamous Cox2 Inhibitor drugs.

This left me again in my right mind although still with serious back pain. I trawled for hours on the web to try and find some solution. I eventually discovered LDN and took some time to persuade my husband to research it as over the years we had looked at several 'miracle' cure treatments for MS. The only one we had tried was the Carrie Loder protocol, which I found to be totally ineffective.

I then persuaded my GP to write a private prescription for LDN in May 2004. Within four days my life changed completely. Having had difficulty travelling locally in the car and being virtually housebound, I could again travel freely.

It took us about six months to get the dose of LDN right and find an alternative solution for my back problem.

Since sorting out the use of the correct dose of LDN for me and resolving the back pain by separate mechanisms I have had NO further progression of MS.

In summary therefore, LDN has replaced a horrifying concoction of dangerous drugs that had turned me into a zombie and might have killed me by now. No doctor is now suggesting I submit to having my spine chemically cut.

My results with LDN seem to be typical of at least 90% of those or so who are currently using it.

For the newly diagnosed, LDN is very nearly a complete solution to MS.

Jay D, UK
2001 - Multiple Sclerosis
Oct 2002 - LDN

I'm still taking LDN, and it will be my 7th anniversary this October. I've been getting my LDN on the NHS for around 5 years.

I had my first attack back in 1993. I lost the use of many things for a little while - my vision went blurry, balance left me, hands were very weak etc. After 4 months of symptoms, one week in hospital and IV steroids, I came back to 99% wellness and stayed that way until I got pregnant in 2000. That was when my legs started to go numb again. I was officially diagnosed in 2001, and it has been a slow, steady decline since then.

I first read about LDN in New Pathways magazine in 2002, so I thought it was worth a try, especially as a GP was taking it. It seemed a fairly safe risk. I started buying my LDN from Dr Bob Lawrence in October 2002. I didn't suffer any side effects, and within a week of starting it I noticed some subtle improvements - my legs felt a little stronger, my bladder a little more controllable, and I had a little more energy.

But by far the biggest improvement was that my legs stopped 'buzzing'. Since my 1st attack I'd been left with residual tingling in my legs, which meant I found relaxing very difficult. Then I started LDN and the tingling went! It was so nice to be able to sit 'quietly' and relax properly!

Although I have not had massive improvements on LDN, I still continue to take it. I am still tingle-free and I attribute LDN for being my own personal firewall. I don't seem to get half as many colds, bugs and viruses, which is a real bonus being a single mum to 2 school age kids!

When I first started on LDN, I visited my GP and told him I was taking it, so my notes could be updated. A year later he offered to prescribe it for me, but at the time there wasn't a pharmacy in England compounding it in 4.5mg capsules, so I had to decline his offer. Later, Martindale's started compounding it in the right dosage, so I went back to my GP and have been lucky enough to get it NHS prescription ever since.

I support the need for LDN trials as I believe it to be one of the best drug options out there for MS right now, and it's suitable for Secondary Progressive as well as Relapsing Remitting, so I believe everyone should have the opportunity to try LDN.

Jayne T, USA
2000 - Relapsing Remitting Multiple Sclerosis
February 2009 - LDN

Throughout my life, I've had many blessings, the love of my parents, 4 beautiful children I raised on my own, and grand, supportive friends. The only one thing that has made a mess of my life was being diagnosed in 2000 with multiple sclerosis.

After a series of 'symptoms' that were dismissed by my GP at first, I demanded to be sent to a neurologist and went through the series of tests that determine whether or not you have 'it'. The diagnosis? Relapsing Remitting Multiple Sclerosis. I was told I had probably already had MS for about 8-10 years.

Shock, denial, anger, mixed emotions and many, many tears held on to me for months. My mother had MS, and as a child, I witnessed her deteriorate. I was scared as hell, and the last thing I wanted was for my children to go through the same thing my sister and I did.

The first thing I did was to Google everything and anything about MS. This was the WRONG thing to do. Everything I read was very depressing and of course, not of an optimistic outlook. I considered the CRAB meds, but after much research on the long-term effects of them, I decided NO. These meds only mask the disease, they do not cure. After they stop working, you are still left with your MS, and damaged organs. In short, I chose the natural approach, with diet, exercise and vitamins... and it worked. I continued to work full time, sometimes 50 hours per week.

In June of 2004, we, as in the children and I, moved into a cute little house, that we thought was ideal, but within six months I went from working and enjoying spare time with my children, to being carried to bed by my son. By January 4/05, I could no longer work. The fatigue, spasticity, brain fog, and weakness in my right leg happened very quickly. By May of that year, I had drop foot on the right side.

I tried everything and anything to 'cure' myself, trying products on the internet, trying new protocols. Nothing happened and the reason for that? Black mould was in the house. Black mould attacks your immune system and that causes you, of course, to deteriorate. So, we moved and moved again, until I was able to get subsidized housing. Through all this, my children, were greatly affected emotionally. All my children had to witness a physically and emotionally strong woman become what I considered to be a pathetic, useless human being. Life can be so cruel.

So, my journey in life continued. Through the meeting of extremely positive people and pushing away the negative, I stopped feeling sorry for myself and embraced my spirituality. I watched 'The Secret' and read, read, read. 'Optimism' was now a new word in my vocabulary.

Despite spending 10 weeks in the hospital after an exacerbation, I looked forward to delving into more research when I got home. So many supportive nurses told me

stories of how they had patients that were bedridden and were now walking and carrying on a full life. So, I decided that was my goal. Never, never, give up.

I subscribe to Dr Mercola's weekly email. He gives advice and information on health issues and the proper way to treat your body. The header of one particular email was, Cure for MS? Well, I did what anyone would do. I read it. The more I read, the more excited I got. Could this be the answer or just another hoax?

Well, the Googling started again, and everything I read was so very supportive. I joined a couple of online groups that support LDN and made contact through Facebook with fellow MSers who were on it, then made my decision.

I gathered all my info, and armed with said info under my arm, went in to see the doctor. I told him of LDN and what it does and gave him the websites to look at. He was so impressed with my research that he signed the script right then. Even now, I remember how ecstatic and lucky I felt to have such a supportive doctor! That was four months ago.

So, I found a compound pharmacy in Toronto and asked them if they could do compound it. My filler is acidophilous, and I started at 3mg per day. I know that some recommend starting at 1.5mg, but being me, I couldn't wait for that. The first night after I started to take it, I couldn't sleep at all. Lesson learned. I then took it just as I was going to bed. The next night, I slept like a babe and had the most wonderful, real dreams!

Side effects? Yes. In the first week, my spasticity increased. As stated in all the LDN groups, sometimes the worst symptoms may be exacerbated, but they do not last long. My energy level increased almost immediately and I stood! I am in a wheelchair, and have been for about one year, so that one simple thing to the average person, enthralled me!

I continued to make strides, until my one doctor put me on Baclophen. It did not sit well with me and turned me into a pile of mush. So, back to square one. Now, since then, excitedly as I report this, my speech is back to normal. (I had no idea my speech had been affected until my friends, point blank, told me how good I sounded now.)

Personally, ugh... my bladder and bowels are back to normal and the brain fog is almost non-existent. My eyesight is getting better. And fatigue? A thing of the past... but I listen to my body, just as any average person should!!

I believe in LDN so much. I tell everyone who has any autoimmune disease about it. It's not just for MS. I created an LDN page on my Facebook, to provide information, and now I'm writing this letter in full support... I've also started a petition requesting governments worldwide to help with funding of clinical trials of LDN, to make physicians and pharmaceutical companies more aware. This petition will be joined with another, to get the numbers higher.

All LDNers believe strongly in this magical little pill. Not only does it work, it is very cost effective at less than \$35 per month as opposed to millions being spent by the government on meds that are questionable, to say the least. Instead of investing in more weaponry, how about investing in saving lives?

So, four months after I started, and only four months, I have not felt this well, in ages. Is this the end of my story? No, it certainly is not. I will not give up the LDN, will keep up with the physio and when I am walking again, never again will I take for granted those little things that a 'normal' person can do. Walk or run to the store, go for a hike, put on my own shoes, reach that box of cat food way up on the top shelf... the list goes on.

I will thank my beautiful, supportive children by walking beside them, and thank my lovely supportive friends. Oh and importantly, Dance!!!!

40

Jeannine E, UK
August 2000 - Multiple Sclerosis
March 2009 - LDN

I have been on LDN for 6 months now.

I didn't expect to feel any difference for at least a month, but in the first week my fatigue was a lot better.

I didn't even notice it at first until I realised everything I was doing was easier to do and accomplish.

Then the spasms eased... I went out to dinner with friends and got up from the table by myself and started walking out with my cane. I stopped, because I then realised that no one had to help me walk out! I am usually all cramped up and can't straighten my legs.

I am not in pain anymore at night with my spasms. I still get them but they are easier to deal with now. The last time I saw my neuro he wanted me to do Rebif as well. I have spent the last nine years on Copaxone, Avonex, Rebiff and IVIG infusions and have been very, very sick.

I feel like I have my life back now so I said "No"... I don't know if LDN slows MS and I don't care. My day-to-day life is so important. I can now work 3 hours from home as well as go out, see friends, go to the grocery store, etc... I would rather have this and enjoy the ride than be sick all the time and have no life. I had 15 lesions while I was taking all the standard MS meds.

LDN is working.

41

Jeni S, UK
1997 - Diagnosed plaque psoriasis
April 2009 - LDN

I've had plaque psoriasis all over the place, including my face, for about 12 years now and in the past have used mainly dovonex, dovobet, and other sticky creams. I've also used UVB a few times, which worked well the first time but not so well after that.

I've been taking LDN now for about 4 months. I started at 1mg per day and gradually increased the dose. I'm now at 3.5mg. I didn't really notice much of a change for the first couple of months, but the psoriasis has definitely faded over the last month or so and I can even see skin on my knees (total novelty!).

My face has also completely cleared up. Obviously this has also coincided with summer, so the sun may have played some part, but it is better than it has been for a long time, so I feel that the LDN is definitely helping. Hopefully it'll continue to improve. I've had no side effects from taking the LDN and it's reassuring to know that the drug has been on the market albeit at higher doses for other uses for quite a few years.

42

Jennifer F, Australia
May 2009 - Ankylosing Spondylitis (type of arthritis)
June 2009 - LDN

After years of CFS/ME Hypothyroid diagnosis, I undertook tests in May 2009 for Ankylosing Spondylitis (AS).

I started LDN in June 2009 for Ankylosing Spondylitis, a type of arthritis, as well as high CRP ESR Inflammation levels. Following my doctors instruction I took 1.5mg LDN at night, which was to gradually increase until I reached a maximum dose of 4.5mg.

I experienced no vivid dreams or insomnia that I had read others had experienced and had mild easing of hip and thigh pain in the first week. Now as a very gentle and even-tempered person with a huge sense of humour, I was surprised when I started to become irritable and snapping at everyone. If I had a dog I would have been growling at the poor thing.

I increased my dose to 3mg and had the benefit of 50% pain relief, able to stand straighter and stronger. I had previously only been able to stand for 3 minutes. I was particularly relieved to find that I could breathe easier and deeper.

During this time I needed afternoon sleeps from 2pm, and the need grew. I was now feeling totally exhausted all day long, having to force myself to shower.

I didn't make my bed or wash my sheets for 3 whole weeks. My exhaustion was so great I was becoming daily more and more depressed unable to function. Yet at the same time, I could visually see improvements, the deep redness between my ankles and knees was receding, open cuts were healing, and pain was easing, so I knew something good was going on 'inside'.

I increased to 4.5mg thinking this would be the answer and I would break through to the other side of whatever I was experiencing, however, my depression just got worse and worse. Unable to dress upon waking, forget brushing my teeth... far too hard... and now I can't wait to go back to bed to experience a deep sleep from 2pm until 6pm. Also keep in mind that I am sleeping deeply from 10pm to 7am each day.

I felt caught between a rock and a hard place, 50% pain gone and visual healing - yet severe depression and incapable of any activity.

Having decided after 4 weeks that this was NOT right, yet knowing I was healing 'inside' I decided to take a few days off LDN. Oh great - here is the pain whooshing back. So what on earth do I do now?

I had listened to an interview with Dr Zagon who said it didn't matter what time you took the LDN, and despite screams of 'night-time dosing only' from devotees, decided to go back to 1.5mg but take it in the mornings.

Pain went back to 50% relief after 2 days and I just got some 'buzzing' in my head (now gone). I was tired but not, 'can't get off this chair or stop staring into space' tired.

The exhaustion lifted, and I started to be able to function again. Sheets got changed on the bed YAY !!!!! Family came out of hiding, but now I have another fun experience.

As a London born Cockney now living in Australia, my cuppa Blitz tea has been my best friend in all of life crisis - and now it tastes like 'dishwater' and the sugar is particularly foul. I can't eat anything, as food now has this most dreadful taste. I had experienced this a few years ago after anaesthetic and couldn't eat or drink for a week - my gosh, what on earth is happening to my brain chemicals? The upside is that I should lose weight, it should be falling off of me any day now. Oh but to loose my 'cuppa tea' is like loosing my best friend...

One week on, I can again enjoy my cuppa, life has become much better and there is NO WAY that I am going back to night-time dosing. I did slip in a night time dose, just to see, and went straight back to 'can't move- can't function and I think I will sit here and stare at the clouds.'

I would also at this point mention the importance of having a no or low starch diet; that means, no bread, biscuit, potato, soy nor anything processed - you know the story. I ate some unsalted cashews (hidden starch) and the pain increased. So it is very important for me to make sure I help the LDN by not sabotaging the benefits by eating incorrectly.

Whilst I have read so many ultra positive, bordering on miraculous stories about LDN - my story is just a real world 'it was hard getting here' experience. I believe that we need

to speak honestly of our experiences in the hope that we all learn something from everyone's situation.

I move on, confident that only good will come from taking LDN morning dosing combined with a low starch diet, and so I look forward to reviewing how far I have come in 6 months time.

And I have just noticed that the once huge ganglion cyst on my wrist has greatly reduced and is a tiny size I can only just feel now. It used to stick out... how good is that, and again, it makes me wonder what is going on inside where I can't see. It was there last week... and had been there for over 5 years... interesting.

I have stopped LDN as symptoms continued to deteriorate. Seems that mercury toxicity, confirmed by hair analysis, 1.44 (0-1) was being released, causing the symptoms, plus the metal taste in my mouth, tingling tongue and worsening headaches - just had to stop. I have been sicker than I have ever been in my life the last few weeks, but I put that down to the mercury trying to get out NOT the LDN

I am 'thinking' that the LDN started to throw out the mercury from the body but I can't find any references or past experiences by anyone so far as I search the forums. I think LDN is the bees knees and 'when' I have chelated all this mercury out of my body I will get back on it to re-heal. I have found suggestions that mercury is the core cause of Ankylosing Spondylitis (Andy Culter). Ah life is such an interesting journey.....

43

Jeanette M, USA
1987 - Multiple Sclerosis
30 June 2009 - LDN

I am writing to LDN Trust to express my gratitude for the opportunity to experience LDN for my illness of M.S.

I was diagnosed in 1987, in my late 20s. I was halfway through graduate school in psychology, and had just had a baby. Upon diagnosis, I was given tegretol, noretryptiline (antidepressant), and solumedrol, just to name a few. After continuing on this track for a few more years, I turned my focus to herbal medicine with fairly good results.

But then, three weeks ago, I read online an interview with Dr. Burt Berkson, M.D., describing the benefits he has seen in patients with LDN. The article convinced me to request from my local doctor a prescription for LDN. For the first time, I feel like my life could possibly brighten (maybe a lot!) regarding present symptoms - my gait (a limp), cognitive ability (aiding my short-term memory loss), and fatigue (which is most of the time).

I think this drug could change people's lives. This is day 14 for me on LDN, so I'm thinking (hoping) it's still in process. I'm not sure how long LDN takes to kick in. If it has completely already, I'll have to go for a long walk and see how my leg does as well as other symptoms. If it takes longer, I'll email you back in two weeks or so, and let you know.

44

Jill G, UK
March 2007 - Multiple Sclerosis
Sept 2008 - LDN

I started to take LDN in September 2008.

I didn't have immediate results, however over time I have noticed a marked improvement in my bladder. I have less spasticity & the tremor in my right arm has reduced.

My balance, coordination, and walking speed are better. So much so that I have adopted a rescue dog and we now go out on walks together.

Before taking LDN I had to make frequent trips to the bathroom due to urge incontinence, especially at night which disturbed my sleep.

My balance was very poor & walking difficult. This meant I didn't leave the house unless absolutely necessary.

After taking LDN my bladder is functioning a lot better, and I sleep soundly at night without being disturbed.

My balance and walking have improved considerably. This has given me confidence to achieve my goals in life, which before didn't seem possible. Thanks to LDN I now have an active & positive outlook.

45

John O, UK
24 July 2000 - Secondary Progressive Multiple Sclerosis (SPMS)
February 2008 - LDN

I have secondary progressive MS and have been taking LDN for about 18 months now. It's fair to say that it has changed my life.

I am able to do so much more now and my quality of life has improved no end. I am able to stay at work and my colleagues have noted a positive improvement in my movement, etc. I am a police officer but sadly whilst it's good, the use of LDN hasn't improved things for me enough to allow me back to operational duties!

I was so enthused that whilst attending my MS physio class, I spread the word about LDN. Judging by my improvements (I was able to get on the floor and participate in floor exercises) a number of my classmates approached me on its availability and how to get it!! They now take the stuff!

Thank goodness for LDN.

46

Jon C, UK
1986 - Secondary Progressive Multiple Sclerosis (SPMS)
April 2009 - LDN

I have MS, diagnosed in 1986 and now secondary.

I took beta-interferon for 10 years until it became apparent that my MS had altered from RR to Secondary.

I have only been taking LDN for four months, having heard of it from a friend. There is no doubt whatsoever that it has improved my mental acuity, coordination, physical condition and wellbeing. I am certainly not an example of a 'miracle cure' but I have already derived definite benefit from LDN treatment.

I work as the Curator of a large collection within a major Stately Home and this treatment has certainly made it easier for me to work effectively.

Jon S, UK
1995 - Multiple Sclerosis
July 2005 - LDN

I was diagnosed with MS in 1995. By 2000, I couldn't work full-time and had to rely on a wheelchair to get around.

I'm over 40 and a father of 3. Just getting going in the morning used to take up to an hour, and that's with help from my wife and children. At more than 6ft tall, hauling me out of bed is no mean feat.

Once I had got up, which itself could take half an hour, I was dragged to the top of the stairs because I couldn't bend my legs. I then had to shuffle down the stairs on my backside, like a child. Once downstairs, the ordeal wasn't over. I'm a writer, so I had to haul myself into a chair next to the stairs, which would then be pulled over to the computer where I'd try to focus long enough to write a few sentences.

One of the aspects of MS is not being able to concentrate and, with a family to support, that was very frightening. Also, illness takes its toll on family life. I have since split from my wife, but my children are still with me.

My neurologist only offered the two conventional types of treatment on the NHS: steroid injections which reduce inflammation, or the drug interferon, which works on MS patients' dysfunctional immune system. I wasn't keen to take more steroids as my dose was already high, and I disliked the flu-like side-effects of the conventional treatments.

I discovered a drug called Naltrexone on the internet. Anecdotal evidence indicated this to be effective in treating MS.

Within three months of taking it, I could leave my wheelchair and get about with a walking stick inside. My concentration also improved, and I got some independence back.

No drug company will apply to trial Naltrexone at a low dose for MS, because to do so they would have to invest millions to prove it's safe and works. However, the results of such trials would be of little consequence to MS sufferers like myself who don't need to be convinced.

I now move around the house on a frame and need the wheelchair only for longer outdoor trips. I hope one day I will be able to walk unaided again. Only time will tell, but in the meantime, LDN has given me something many with MS don't have - hope.

I've been getting my LDN from the USA via Dr Bob Lawrence since UK supplies of the tablets were interrupted for a while and became unavailable. My GP still won't prescribe it for me, despite endless lobbying by myself and Dr Bob. I can never be without my LDN.

More recently, I've been having Hyperbaric Oxygen Treatment at my local MS Therapy Centre, together with weekly physio, all of which I have to pay for. Currently, I cost the NHS nothing - bar one flu jab a year.

I still feel absolutely fine, but I now have to use a wheelchair every time I go outdoors. I can still drive, which means I remain useful as my youngest son's taxi service. I remain resolute in my dogged belief that not taking aggressive drugs like steroids and DMDs (disease modifying drugs) was the right choice for me.

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Jonathan D, UK
December 2000 - Multiple Sclerosis
4 January 2007 - LDN

From the mid nineties onwards there seemed to be something wrong. Being a sheep farmer, we suspected organophosphate poisoning as we knew of several cases in our area. I was without any rational explanation, was running out of energy with periods of very low spirits, and was from time to time suicidal.

I lost my father in 1996 and just didn't seem to pick up from that point on. There were various visits to the doctor, none of which did much good, but I do thank God that I binned the Seroxat after a few days.

It finally came to a head in the Autumn of 1999, a strange tingling on my right side and several unexplained falls, one of them on flat Tarmac. I went to the Doctor and demanded to see a specialist and was referred to a Neurologist.

I paid to go private and saw him around the 6-10th December 1999. He said, after a lengthy pause, there was definitely something wrong but he could not say what. In mid January 2000 I was admitted to the Neurology ward at The University of Wales Hospital, Cardiff. After around a week of tests, I was diagnosed with Syringomyelia and was introduced to a Neurosurgeon, Dr Vafidis, who sent me home wanting to operate as soon as possible with instructions to ring in if anything changed.

After a very hectic weekend with my children running us ragged, by the Sunday evening I found I was unable to speak. On the Monday Morning I phoned his secretary. I was admitted by 4pm and underwent a Foramen Magnum Decompression operation in February 2000. My symptoms improved greatly for a couple of months but then started to get worse again.

By August/Sept 2000 I was in a state of collapse and was carried into the University of Wales Hospital in Sept 2000. The usual range of tests ensued, such as; MRI scan, Lumbar puncture, urine retention, and one I don't remember the name of which tested my visual fields and reactions, and there were probably more that I have forgotten.

There was the customary delay in informing me that I had MS (I was told in December 2000), and then the Neuro sent me away to get on with it.

Beyond this my memory fades, a lot of water has passed under the bridge since 2000.

From the outset I was astonished by the attitude of the Neurologists who just seemed to want me to go away and get on with it. I had already had acupuncture and used essential oils for healing, I knew there were options out there to help with the MS so I went about finding things that helped me feel better and slowly made progress against the MS.

I won't detail all of the things that helped and instead will jump to December 2006 when somebody (Andy) phoned me up out of the blue, told me all about Low Dose Naltrexone (LDN) and how it had worked for him. Determined to try it, I noticed Dr Bob Lawrence's name on the internet and as he was close-by, I got in touch.

I started LDN on the 4th January 2007.

For a couple of days I was a little groggy, but almost immediately after I found my head began to clear, and hence, the brain fog of jumbled thoughts began to ease.

I didn't notice much more for a few weeks but then found my legs, which had been very wooden, were coming back to life and all of a sudden, sexual function returned. In Easter 2007 I led some French friends on a country walk in to the waterfalls country. It's quite a long walk and something I thought I would never do again. I had gone from struggling round town on two walking sticks to boldly striding out across country.

I remain fit although the MS does give kick now and again, especially if I forget to take LDN as occasionally happens, or if I overdo it. I still seem to have a problem with hot weather, so I still hide indoors when it's hot.

This description did not work out as brief as I'd hoped, but I do hope it goes a fair way to describe the most wonderful thing in my life - Low Dose Naltrexone.

Update – January 2009: I'm still doing well on LDN.

I received a letter today from my GP declining to prescribe LDN on the National Health Service - so I will be buying it on a private basis now.

Joyce C, USA
2001 – Hepatitis B
July 2007 – LDN

I'd been waiting for years to become a mother. When I learned that within a few months I'd be flying on a plane to Asia and would finally be united with my new, wonderful 11 month old daughter, I lay awake at 3 o'clock in the morning excited about what the future held, and thinking about how to decorate my future daughter's bedroom. I wanted her to be surrounded with a special room in her new home-to-be, constantly reminded that she is loved and a precious gift from God. I remembered a picture I had just purchased with 3 Angels dancing and rejoicing with the inscription 'The Angels Danced the Day You were Born'.

That message became the inspiration for her bedroom. I wanted to write those powerful words into the wet paint on the walls of her room - symbolic of drawing those meaningful words into the fresh canvas of her heart and life. However, I had never tried cursive writing in wet paint before and did not know if it would succeed. But what did I have to lose, and it could actually work - so why not at least try it and see the results? Well, I tried it and it worked beautifully! My experience with hand painting my daughter's room is something similar to my experience with Low Dose Naltrexone (LDN), as I will share in our story of great 'Grace & Hope'.

After arriving home, my daughter Grace (not her 'real' name), underwent normal adoption blood work to check for HIV/AIDS, Hepatitis, parasites, etc. The doctor called back a few days later and asked me to sit down because she had some news to share on Grace's lab results. She had tested positive for Hepatitis B (Chronic Active). How could that be, I wondered? She had been tested for Hepatitis in the orphanage and had a clean health record. After the initial shock, I realized that she was truly a gift and we would face this disease with hope and prayers for a healing miracle.

While Grace's Hepatitis B had very little impact initially in our lives (besides routine lab results), Grace's food allergies and eczema continued to spiral downwards. From 2002 onwards, she'd developed a new food allergy every few months - and feeding her became very challenging. She became allergic to all dairy, corn, soy, nuts, egg, wheat, and other fruits and vegetables. Additionally, her eczema was so severe that her skin was constantly raw and red. In 2005, I became desperate.

The conventional treatments offered by her Pediatrician, Allergist, and Dermatologist had not delivered improvement, so I started to investigate and use Complimentary and Alternative Medicine (CAM) protocols to see if we could heal the underlying causes of the food allergies and eczema. Based on my research and additional consultations with a Functional Medicine practitioner, we concurred with adding Antioxidants, Probiotics, Essential Fatty Acids (EFA's), and liquid vitamins/minerals to her diet. (Note: Functional Medicine uses both Conventional & CAM approaches to holistically treat patients - (www.functionalmedicine.org)).

These combined efforts finally started to improve my daughter's food allergies and eczema, but we also saw another benefit. Her immune system started to recognize and fight the Hepatitis B virus.

In children, due to their immature immune system, the body is often not able to mount a successful attack to totally eliminate the Hepatitis B virus. When the body's own immune system starts to fight the virus, very often the liver enzyme levels (the ALT and AST particularly) begin to rise. This is known as the 'Immune Clearance' Stage because the body's immune system is trying to 'clear' the virus.

If the liver enzymes are raised for an ongoing period of time, it can damage the liver with inflammation and scarring. It's a paradox that the good the body is doing while fighting the virus is also damaging the liver.

My daughter's liver enzymes and viral load started going up in 2006, and her liver biopsy result in Spring 2007 rated both her 'Inflammation' and 'Scarring' scores at 2 (mid-range in the scale 0-4). Her Gastroenterologist wanted to begin either Interferon treatments, or enrol her in a Pediatric Anti-Viral drug trial for a new drug, Entecavir, that was commencing within 6 months. Her doctor contacted Johns Hopkins (Baltimore, Maryland, USA) and together we determined my daughter would be a good candidate for the upcoming Entecavir Pediatric drug trial that was starting in the near future.

While waiting for the Entecavir drug trial to start I went back to the medical professional who had helped us so much over the past two years with Grace's food allergies and eczema (the Functional Medicine practitioner). She was excited about my daughter getting into the Entecavir drug trial, but when I asked her if she could think of anything that might help boost Grace's immune system prior to the trial, she mentioned 'Low Dose Naltrexone' (LDN). She'd recommended LDN for other medical conditions where the immune system needed further stimulation, with success, so she proposed LDN as a possible solution. She said I should research LDN at <http://www.ldninfo.org>, to see if it was something we wanted to try, and left the decision to me.

For approximately 2-3 weeks, I poured over the ldninfo.org website, which had a wealth of information. LDN had been used by many patients with various conditions; Cancers, Autoimmune Diseases, and HIV/AIDS. All the info indicated it helped the immune system function properly (which is exactly what I was looking for to combat the Hepatitis B virus).

The website briefly mentioned that LDN had been successfully used in Hepatitis C patients. I also reviewed other medical research, including the National Institutes of Health (NIH) PubMed website, into the growing area of research into how opioids and opioid antagonists can positively or negatively affect the immune system (depending upon how they are used and dosage levels). I've included some of those NIH/PubMed studies at the bottom of this story as a reference, particularly those relating to the liver and Naltrexone.

One concern I had was the 'black box liver warning' for Naltrexone. I did further research into the liver warning and found the warning was based on very high doses of Naltrexone, at 300mg per day, where some liver anomalies had occurred in obese patients.

Dr Jaquelyn McCandless and other doctors had been safely administering minuscule doses of between 1mg and 3mg per day (a tiny fraction of the maximum safe dosage)

to treat children with Autism. We rationalized that since LDN had been so helpful for other immune related illnesses, and the side affects were minimal (transitory sleep disturbance when starting LDN being the main side affect), and it was so inexpensive (less than a \$1 per day), that we'd like to try it. I grew eager to start LDN before the Entecavir study (to see if maybe the two together would help her).

What did we have to lose in comparison to what we might gain? But, before we started LDN, I wanted to ensure being on LDN would not preclude Grace from getting into the Entecavir Study at Johns Hopkins (because back then, we had no idea how good LDN would actually prove to be).

I spoke with our Pediatric Gastroenterologist in June 2007 to check he was okay with us trying LDN (especially as he was not the prescribing LDN doctor) and to make sure he was aware of our attempt to prime my daughter's immune system with LDN before the trial. While he didn't know if LDN would do any good, he didn't think it could do any harm, since he had other liver patients on a higher dose of Naltrexone for pruritus (severe itching caused by other liver conditions). To maintain eligibility for the trial, we agreed we'd stop the LDN once the Entecavir study actually began. I also consulted my daughter's Pediatrician to ensure she was also aware of our plans. Both doctors concurred with us trying LDN.

In July 2007 we started my daughter on a very minimal dose of 1mg Low Dose Naltrexone (LDN). Within one month of starting LDN, in August 2007, we had liver laboratory tests completed to see if LDN was having a positive result, and it was. The doctors couldn't believe how good the results were, and ordered more tests to confirm.

LDN in July 2007. We saw a remarkable decrease in liver enzymes, from ALT 196/AST 203 in May 2007 to the normal range of ALT 26/AST 38 in August 2007. Her liver enzymes were the lowest ALT/AST results we'd seen since her diagnosis in 2001.

Additionally, we saw a significant viral load reduction from 59.2 million in February 2007, to 53.3 thousand in August 2007. At that point we no longer even qualified for the Entecavir study - yippee! The Advanced Practice Pediatric Nurse who prescribed the LDN was ecstatic with the results.

Incidentally, I called my daughter's Pediatric Gastroenterologist when we got her lab results in mid-August 07. I said to the doctor, "Isn't this good news"... He responded..."No ... this is GREAT news!" We discussed that LDN appears to be resulting in similar responses as can be achieved with other anti-viral drugs.

The doctor said he had one teenager on Entecavir and this patient also saw dramatic results within the first month (similar to my daughter's impressive viral load decrease). However, the advantage of LDN was that since it wasn't an anti-viral Hepatitis B drug, but instead helped her own immune system to fight the virus, we didn't have to worry about the anti-viral resistance that can be a problem with other anti-viral drugs.

Also, if at any point the LDN stopped working in the future, we always had the option of starting anti-viral drugs (without the worry of her already building up Anti-viral drug resistance). The Gastro doctor was not the prescribing doctor of the LDN, but he said to keep on doing what we were doing because it appeared to be working!

Between the Sept 21, 2007 and Nov 15, 2007 lab results we'd stopped giving Grace some of the antioxidants we were previously using for food allergies and eczema (since

those conditions had improved significantly). Because we felt this change may have accounted for the slight increase in Viral Load in Nov 2007, we resumed all supplements, and increased the LDN dose to 1.5 mg nightly.

In February 2008, 7 months into our LDN/Antioxidant protocol, Grace had Sero-converted, going from HBeAG (e Antigen positive) to HBeAG (e Antigen negative), and she'd gained the HBeAB (e Antibody positive). This was an outstanding result! These same treatment outcome results only happen in approximately 30% of children on Interferon treatments, so the above treatment may possibly compete with Interferon!

It is now July 2008. Grace's liver enzymes are still in the great range. She has maintained her HBeAG (e Antigen) seroconversion to HBeAB (e Antibody). Her Viral Load has very slightly increased from the undetectable range on 8 Feb 2008 to 551 (but this is still very, very low compared to the 59.2 Million in Feb 2007).

Over the past year (since beginning LDN in 2007), we've achieved excellent results below the max 3mg dosage level (at 1mg and then 1.5 mg nightly). While my daughter has done extremely well, we're going to increase the dose to 3mg a night, effective 17 July 2008, as she's grown considerably over the past year. The 3.0 mg dosage is believed to be the optimal dosage for children. (Note: For adults the optimal dosage target is 4.5 mg nightly to obtain the maximum benefit to the immune system.)

Besides our blessing of healing for Grace's Hepatitis, we have also seen fantastic results in her eczema and food allergies due to the multi-pronged approach of LDN with the Antioxidants, Probiotics, and Herbs we commenced in 2005. Grace has no more eczema - her skin is now like silk for the first time in her life. Additionally, her digestive tract has been healed, thus eliminating the extreme responses she had to various foods. She is now able to eat every food (in moderation) with no more allergic reaction. That is a real miracle, and as her body is better equipped to absorb nutrition from what she eats, this bonus has contributed to her improved health.

It appears that my daughter's body may have entered into the 'Immune Clearance' stage with the Antioxidants, Probiotics, Herbs, etc. we began in 2005. When LDN was added in 2007, it helped further stimulate her immune system to dramatically fight the virus. In clinical studies, Naltrexone demonstrated an increase in the body's Natural Kill Cells (which fight viruses). Therefore, I believe that LDN might also help jump start the immune system and take a child from the 'Immune Tolerant' stage to the 'Immune Clearance' stage in a safe and effective way!

The LDN website (ldninfo.org) is full of information that you can print out and give to your doctor. Also, the website has a link to the main LDN Yahoo Group where you can learn about other people's success with LDN, and find out about other 'splinter LDN groups' like mine that focus on specific diseases that LDN has benefited.

Clinical trials of LDN for other diseases (Multiple Sclerosis, Crohn's, HIV/AIDS, Fibromyalgia, etc.) have been completed (or are currently being completed) that indicate the immune modulating effects of LDN. At this point, controlled clinical trials need be undertaken by the medical community in order to prove the efficacy, safety, and dosage recommendations for children and adults. Only when clinical trials are undertaken, will we be able to 'prove' scientifically that LDN really helps to boost the immune system in fighting the Hepatitis virus. However, we need to ask the National Institutes of Health (NIH), FDA, and others in the Medical Community to fund clinical trials for LDN and Hepatitis.

This is one of the end goals of the Yahoo Group that I recently established, 'Hepatitis Children and CAM Alternatives'. Our focus will be on informing other group members, but also documenting our treatment stories in enough detail that we can give it to medical researchers. Our group welcomes both adults and parents of children with any form of Hepatitis (B, C, Autoimmune, etc.) to join us in our journey of healing.

My daughter's Gastroenterologist, Pediatrician, as well as the prescribing APRN are all very excited to see the results we have achieved!! Her Gastro believes that there is definitely merit in conducting controlled clinical studies in LDN in Hepatitis in order to scientifically document the efficacy, safety, dosage recommendations, etc of LDN in fighting the Hepatitis virus. He will be discussing our case study with local Gastroenterologists (including a Gastro from Johns Hopkins) to discuss this possibility of initiating a clinical study. Yippee!

Also, Dr. David Gluck, who is the editor for the official LDN website (ldninfo.org) has seen my Treatment Success Report (i.e. a similar copy of this report indicating our Seroconversion, undetectable viral load, and great liver enzymes). He is going to forward our report to Dr. Leonard B. Seeff at National Institutes of Health (NIH)/ National Institutes of Diabetes, Digestive and Kidney Diseases (hepfi.org/learning/authors/seeff.htm). In the future, when there are other LDN / Hepatitis Treatment Success Reports for other patients posted on the new Hepatitis_Children_and_CAM_Alternatives Yahoo Group, I will forward them to Dr. Gluck, who in turn will then forward them to Dr. Seeff at NIH.

I spoke with a Gastroenterologist from Johns Hopkins Medical. While her original intention was to tell me the bad news about the delayed Entecavir study that my daughter was enrolled in last year, I was happy to be able to give her the great news about our successful seroconversion. I was very grateful the doctor was willing to talk to me for 10-15 minutes about my daughter's Low Dose Naltrexone (LDN) case study, as well as the exciting research being conducted by Pennsylvania State University (PSU) / Hershey Medical Center into the impact of opioids/opioid antagonists on the immune system. She also indicated NIH is looking to do clinical research on Hepatitis and I suggested LDN as a candidate of one of the trials. So I'm willing to advocate in any way I can to get the necessary funding to research this exciting area!

I also spoke with one of the researchers at PSU / Hershey Medical Center who assisted in the LDN / Crohn's Phase I study (ncbi.nlm.nih.gov/pubmed/17222320) and is assisting in the current Phase II LDN/Crohn's study (The Effects of Naltrexone on Active Crohn's Disease) and the Pediatric LDN/Crohn's study (The Efficacy of Low Dose Naltrexone Therapy in Children With Crohn's Disease). She works in the Gastroenterology Department and was very interested in our LDN/Hepatitis B case study. They are also working on other therapies (besides LDN) for Hepatitis C.

Dr. Jill Smith is one of the prime researchers, along with Dr. Ian Zagon and others at the Hershey Medical in how opioid antagonists can help the immune system. Dr. Smith had great words of encouragement in her following statement, as part of their Crohn's Disease Clinical Study (medscape.com/viewarticle/555290):

' ... "We do not understand the entire mechanism by which the opioid antagonists work to help Crohn's disease, but our basic science studies suggest that the low dose naltrexone increases endogenous enkephalins and endorphins, and these in turn improve (rather than suppress) immunity and cause healing of ulcerated mucosa," Dr.

Jill P. Smith from Pennsylvania State University College of Medicine in Hershey told Reuters Health ... Dr. Smith added, *"I believe the main point for physicians and patients is to have hope that perhaps a new era of treatment may be on the horizon, an era of biotherapy that may improve and restore health and healing to the bowel and not at the expense of harming the body's natural immunity."* ... ‘

I have forwarded an email to the doctor at Johns Hopkins, the researching doctors/nurse at Hershey Medical Center, and my local Gastroenterologist trying to garner further interest in initiating a clinical trial for LDN. I included a number of web links to sites discussing LDN.

Additionally, we have sent our Case Study to National Institutes of Health, Johns Hopkins, and Pennsylvania State University/Hershey Medical Center in order to further spur interest in LDN and Hepatitis research.

We are truly grateful, appreciative, and awestruck by this miracle and have been blessed by God's mercy in this welcome healing! I personally believe LDN may be a safe, viable alternative to the current limited drugs that are available for children (as well as adults) with Hepatitis and other immune related diseases.

Every day my daughter is reminded when she enters her room (with the hand painted walls) that she is a precious gift and 'The Angels Danced the Day You Were Born'. I'm glad that I was willing to try something different - her room turned out beautifully. Maybe you could say I 'saw the handwriting on the wall', and chose to try something different (LDN) to help her immune system. LDN's results have also turned out beautifully!

Update: June 2009: We have continued our success on LDN with my daughter's Hepatitis B – her sero-conversion of the ‘BeAG’ (e' Antigen) and gaining the ‘BeAB’ (e Antibody) has been maintained over the past 18 months. Additionally, her viral load is undetectable, and her liver enzymes are in the normal range.

On the Hepatitis_Children_and_CAM_Alternatives Yahoo Group, we now have 121 members. Of these, 10 Members with Hepatitis C, 2 Members with Hepatitis B, and 1 Member with Auto-immune Hepatitis have started using LDN. Thus far, every person who has tried LDN has seen improvement in their condition once lab results have been taken after starting LDN (either by reducing liver enzymes and/or viral load). We are excited with the possibilities that LDN offers to the Hepatitis community...

I will continue to advocate for funding for LDN and Hepatitis...it offers a great possibility as an alternative, affordable treatment in our fight to slay the dragon!

I went to the Hepatitis B Foundation Patient ‘B Informed’ Conference on 26-27 June 2009, shared this Hepatitis B case study among patients and doctors, and promoted the need for LDN trials. Additionally, I shared the LDN success of two other members of the Hepatitis_Children_and_CAM_Alternatives Yahoo Group who have seen dramatic results in the liver lab results for their Hepatitis C.

Three Cheers for Answered Prayers & LDN! ~~

Judy H, USA
October 1995 - Fibromyalgia
21 January 2009 - LDN

I was diagnosed with Fibromyalgia in the fall of 1995. I woke up one morning and was in so much pain I couldn't move. I was very lucky however, because my physician was familiar with Fibromyalgia and diagnosed me right away. Unfortunately, all the medications he put me on either gave me bad side effects or didn't help at all.

I think I may have been predisposed to have Fibromyalgia because of genetics, but I know the stresses of life and various illnesses may have contributed also. My mother was a type 1 diabetic when she got pregnant with me. She had been diagnosed when she was 18 and was 24 when I was born. That meant that I weighed 9 lbs 10 oz and was born insulin dependent. Memories of my childhood include many times when mom would pass out because of difficulties with keeping her blood sugars level. Later a doctor actually asked her if he could tell her story at a medical conference because of the type of diabetes she had. He explained that sometimes her body would produce insulin and sometimes it wouldn't.

Even with all her health problems, mom tried to be a good mother. And my father, a minister, tried to be a good father. Unfortunately, I was still sexually abused by a friend's grandfather when I was five. I remember my parents being shocked when I told them, but nothing was ever said or done about it again. I felt as though I had embarrassed them by saying anything, so the second time I was sexually abused, this time by a cousin when I was eight, I didn't tell anyone. It was also around this time that I caught diphtheria and nearly died. The doctor gave me penicillin, but I had an allergic reaction to it. Somehow, however, my fever broke and I recovered.

When I was a teenager and began having my period, I would have terrible pain with it. I was also very irregular and would have them only once every two to three months. Later I found out this is a sign of endometriosis and Poly Cystic Ovary Syndrome. I've had a fighting battle with my weight all my life, but by heavy dieting and exercise I was able to get pregnant with my five children. Unfortunately, that caused a lot of yo-yo dieting which gradually made my health worse. I eventually had pancreatitis and had to have my gall bladder removed. Then I was diagnosed as hypothyroid and put on Synthroid. I also had high blood pressure and was treated for that.

About a year after I was diagnosed with Fibromyalgia, I was diagnosed with Restless Legs Syndrome. I started taking Mirapex, which did help a little. Later a sleep study would show that I also have Periodic Limb Movement Disorder. However, the constant pain all over, numbness in feet and hands, twitching of muscles and total exhaustion of my fibromyalgia, made it nearly impossible for me to do anything. So in 1997 I applied for disability. I was turned down. I appealed. Again I was turned down. I asked for a hearing before a judge. He ordered a psychiatric examination, which I must have failed because I finally got my disability.

By the year 2000, I had gained another 100 pounds, putting my weight at over 300 pounds. I hated it and decided to have gastric bypass surgery. I did lose about 100 pounds, but the weight loss didn't help the pain from the Fibromyalgia. The extra weight had already done its damage though, and I had to have surgery on my back for spinal stenosis. Also, because of constant fever and sore throats, my tonsils were removed. Later that year, I had the endometriosis and Cystic Ovary removed.

Every time a new drug would come out for Fibromyalgia, my doctor would try it on me. It seemed, however, that the side effects always outweighed any benefits. And I had to constantly alternate pain medications because of stomach upset or other problems. Somehow I kept going, though, mostly by taking a lot of Tylenol. Unfortunately, it never did more than barely take the edge off the pain. I think I probably also had Multiple Chemical Sensitivities, but my doctor never confirmed it. And then, because I couldn't be very active, I started to regain much of the weight I had lost from the bypass surgery. Even though it seemed as though my health continued to deteriorate, I didn't give up. But I did decide I would just have to learn to live with my life the way it was.

In 2007, I nearly died from double pneumonia. It really scared me. I determined I had to do something more about my health. I went on the internet and tried to learn everything I could about the new advances in Fibromyalgia and healthy living. About this time I heard about phytonutrients and began to take a supplement that contained them. I started to feel a little better. Next I started the Atkins diet program and totally changed my diet, cutting out gluten and sugar. I finally began losing some of my excess weight. I even began to feel better as the devastating pain wasn't quite as bad and I seemed to have slightly more energy.

Unfortunately, by this time my spine had started to deteriorate. I had two disks that slid out of place and pinched my spinal cord (Spondylolisthesis). The pain became so severe that I was put on Tramadol (Ultram). Unfortunately, I had a severe allergic reaction to it. I started sleeping 18 + hours a day, and I was so out of it when I was awake, I didn't know what was going on around me. Then my eyes and face started to swell. I tried to go cold turkey, but thought I was going to die.

My doctor's office said I would have to wean myself off Tramadol because it was an opioid drug.

Again I went on the internet, and in the process of learning how to come off Tramadol, I came across a drug called Low Dose Naltrexone.

When I discovered that Stanford University was doing a trial of LDN in Fibromyalgia patients, I printed out a stack of information about it and took it to my doctor. While he had never heard about Naltrexone being used for Fibromyalgia, he did agree to read about it. Since I was seeing him at the time for my back problem, he said he wanted me to have my back surgery first.

I had my surgery December 4, 2008 and was finally able to walk again. When I went to see my primary physician in mid January 2009, he agreed to write a prescription for LDN. **He said he couldn't discover anything about it that would harm me.** I thus started a dose of 4.5 mg LDN at bedtime on January 21, 2009. I was hopeful that this time I had found something that would help, but I'd been disappointed so many times in the past, I was determined not to get too excited about it.

The first night I did fine. No dreaming, but then I couldn't remember dreaming for a long time. I did wake up a couple of times, which isn't that unusual with my Fibromyalgia pain, but I went right back to sleep. I didn't notice anything different when I got up the next morning. Second night, again woke up a couple of times, but this time it took about an hour each time to get back to sleep. Was having a lot of pain in my pressure points. I massaged them until they eased up, then fell back to sleep. Again didn't notice anything different during the day.

Third night, I woke up sweating profusely at around 3am and threw off the covers. I started to chill again after about fifteen minutes, so I pulled up the covers and went back to sleep. I wasn't sure if it was a hot flash or from the LDN. Later that afternoon, I did notice that I seemed to have more energy during the day.

On day four, I again woke up sweating around 3am, but it wasn't as severe as the previous night. When I got up in the morning I realized I didn't have as much stiffness as I usually do. Also, I realized that while I did still have some pain, especially in my pressure points, it wasn't as sharp.

The fifth through seventh days I didn't feel too bad during the day, but by evening I was totally exhausted and I started sleeping 11 to 12 hours at night. I didn't wake up in pain as many times during the night, but I did realize that I was dreaming. I didn't really remember what the dreams were about, but just remembered that I had actually had a dream.

Around the tenth day I realized that my morning stiffness wasn't as bad as before. And I definitely had more energy and less pain. I never expected to notice any changes so quickly.

On the 18th day I woke up between 2-3 am and realized I had been dreaming. And this time I actually remembered the dream. I did stay awake a couple of hours afterward, but finally went back to sleep. When I woke up I felt so good, I ended up overdoing it. I actually straightened the living room and vacuumed the floor. I haven't been able to vacuum for I don't know how long. I've always had to ask my husband to do it for me. He still moved the furniture around, but I actually did the vacuuming. Of course, later I started to notice a lot of pain and exhaustion. It continued through the night and I woke up every time I turned over. However, when I woke up the next morning, I again felt pretty good. If I had tried that before, I would have been in bed for a couple of days at least.

At one month, I couldn't believe how much my life had changed. I had so much more energy and I felt so much better. I still had some pain but had been able to cut back on pain meds, taking them just when I needed to instead of around the clock. I still had days where I felt exhausted and awful, and some nights where I felt like I hardly slept at all. And then there were other days where I woke up feeling like I had the best sleep of my life. Some days I didn't think the LDN was working, and then other days I was so excited because it actually felt like it was.

I could get up and not have to hold onto the wall for support. My morning stiffness and pain were at least 50% better.

One thing I didn't expect was with my restless legs. That started to get better also. I had been taking 1 mg Mirapex at about 3-4pm and then another at bedtime. Gradually, I started to forget to take it until later and later in the afternoon. So I cut that dose in half.

Then I didn't need to take any in the afternoon. Then I cut the evening dose to .75 mg and finally .5 mg.

That is something I never expected to ever happen. And I think I'm even more excited about that then how I felt about my fibromyalgia getting better. The Mirapex has some very undesirable side effects, but the relief from symptoms did outweigh the problems.

Another thing I noticed was that my mind seemed clearer. I didn't have as much fibro-fog as before. And most of all, I actually felt like doing things again. In fact I had to watch that I didn't overdo, because I'd start something like cleaning out a kitchen cupboard and forget to take a break.

There was an incident that happened around the beginning of the second month that made me really realize how LDN works.

I caught a very nasty bug of some kind. When I was at my sickest, I woke up two hours after I went to bed and it would feel as though my body's immune system had completely closed down. I felt horrible. I'd stay awake for a couple of hours and then finally drop off to sleep. When I woke up I felt so much better, like my body was fighting off the infection and I was mostly just tired. Then, gradually through the day, I would start to feel worse again. This happened for about 4 days in a row.

My husband kept telling me I should go the doctor, but every day I kept saying I didn't really feel that I needed to. Usually, I would have to get antibiotics when I had something like this, but this time I didn't need to. Amazing. Of course I loaded myself up with vitamins and drank lots of fresh juice, too.

As I write this, I've been on LDN for almost six months. I have come from having daily pain levels of 5-7 to 2-4. I still have to pace myself, but I have so much more energy. In the last 2 months I haven't had to use my walker once. I usually sleep through the night, waking normally after about 8 hours. I had fasting labs drawn that said my liver, kidney and thyroid function are normal. I rarely need to take any pain medication. I would have to say that I feel 70-80% better overall.

For me, I can't say anything bad about the LDN. I think everyone with Fibromyalgia should definitely give LDN a try. What do you have to lose?

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Kathy R, UK

DATE – Primary Progressive Multiple Sclerosis

July 2006 – LDN

I started taking LDN approximately 3 years ago, after reading about it in the 'New Pathways' magazine, then researching it on the internet. My doctor initially prescribed, and continues to prescribe, Naltrexone in the full 50mg dose. My husband crushes a

50mg tablet to fine powder between two spoons, then divides it into approx. 4.5mg doses, each of which he wraps in marzipan. I take one every night just before bedtime.

I have PPMS and since taking LDN my condition has remained stable, I suffered terribly with 'restless legs' at night. Now my restless legs are a thing of the past. My balance has also improved. I used to fall almost daily, and sometimes more than once.

Kim S, UK
1990 - Multiple Sclerosis
2009 - Secondary Progressive Multiple Sclerosis (SPMS)
20 March 2009 - LDN

I was diagnosed with MS in 1990 after a long period of illness and many months in hospital suffering from seizures (I have MS with seizures).

Following that first major flare, my MS settled into Remitting Relapsing - until 2 years ago when I started to get worse and the seizures returned.

I had pain in my spine and increasing loss of sensation in hands, feet, and legs. My ability to walk was impaired. It was incredibly difficult to walk without constantly stopping. Pain and cramps were waking me late at night and early in the morning, my eyesight was worsening, and I was generally on the road downhill... !

I was at my computer one morning in March 2009, feeling rather low, my future looking bleak, contemplating at some point perhaps the unspeakable, and a possible necessity for me... when I came across LDN purely by chance - and this 'chance happening' has turned my life around in a very short period of time.

I called Linda Elsegood (an Angel helping so many of us in need of her compassion and knowledge of LDN), and I started LDN on the 20th March 2009.

I noticed a change within 24hrs! It is an amazing drug that does not cure MS, but has an almost homeopathic effect, in that our own bodies fight the effects of the illness. In the first week I noticed incredible results. My balance improved 100%, and there was no pain when I awoke. I had less fatigue and could walk again for long periods of time without stopping.

I kept diary of my first few months, writing down the amazing changes. In the first week my senses improved. I could smell, touch and taste better. Perhaps when we have MS, we are unaware of just how much it affects all of our nerves until we're lucky enough with LDN to experience the 'before and after' effect.

After 7 weeks and 3 days, I could wiggle my toes in bed and in shoes (still can!). I was able to walk to the supermarket, carry home my shopping bags, then walk up the stairs unaided!

After week 1, I was able to stop taking 1 dose of the clonazepam that I take for seizures, and I could get in and out of the bath with absolutely no problem and even wash my hair.

My balance is now excellent. It's greatly improved, and I'm going to join my Gym again!

Just before the Glasgow conference I shared my improvements with one of the neurologists at the hospital I attend, but I did not get much response. I also told my GP,

but she also did not say too much except that she could not prescribe LDN for me, then asked, "Were there any Doctors at the Conference from England?!"

I gave her some literature to read and I can only hope she did.

Not that long ago, I'd received a letter from my Neurologist confirming I have Secondary Progressive MS. I can only be thankful that LDN came into my life before I got any worse.

LDN is not a cure. I still have MS symptoms, but it has dramatically improved the quality of my life, and I have already become more accustomed to these 'normal' feelings.

During the first six (6) weeks I felt euphoric, because the changes were so dramatic and so quick. I am still in awe of the changes this little drug dose brings, but I no longer feel I need to shout it from the rooftops, or tell absolutely everyone I meet (because they look at me as a deranged woman).

I went to Brighton and was able to go on 'Water Logs' and 'Dodgems' with my young son... a huge achievement!

I notice in times of extreme stress I now experience minor symptoms (compared to pre-LDN). My son was in hospital for 1 day and put under general anaesthetic. I temporarily increased my dose to 4.5mg, which worked, and after 1 week I went back down to 3mg.

I think this is one of the many reasons we need trials done for LDN as the dosage is so important and there are times you just have to be brave and try things out. All of us on LDN are on a rather lonely path in the medical world and those who are not on LDN, but are in great need of it, are being terribly forgotten by the Medical world.

I thank Linda, and I thank the doctors and pharmacists who are brave enough to stand up and help us all. I'm thankful for my good fortune, my favourable co-incidence, and I can only hope that soon everyone who needs LDN will also be given the chance.

I just got back from Algeria last night and this year we had a lovely holiday. I was so much stronger and feeling much more well than last year!

Kristie S, USA
February 2002 – Multiple Sclerosis
March 2008 – LDN

Imagine being the sick child in the family, with tonsils removed at age 6 and having to take liquid nerve medicine because of tummy aches. Imagine always getting a virus!

Imagine as a teen not eating pizza because of stomach pains, and being told all other pains are called growing pains even though you only grew to 4ft 11 ½ inches tall. Then as an adult hurting with muscle spasms, and after trying to find out why you want to sleep so much, hearing the doctors say, “You did too much“, or “Maybe you’re depressed“.

I've been through Gall Bladder removal, cystitis, hysterectomy and always having ‘Inner Ear Infections’, and losing balance for weeks. My eyeball hurts so bad at times I wished I could just take it out for a while. My vision would come and go and the docs would say it's low blood sugar.

I'd wonder why my Mom and Grandma had so much energy and I didn't!

Then in my forties my feet decided to go to sleep! The next day my leg would go to sleep and hurt so bad I couldn't sit, stand, or lie down. I'd have to keep moving to make the pain tolerable, only I'd stumble and couldn't regain my balance again!

So I'd go to my doctor, almost convinced by now that he was right and that it was just in my head, or thinking, ‘This is a fine time for my inner ear problem to act up!’.

And again, the doctor would dismiss my concerns with, “You probably pulled something in your back or hit your leg. If it doesn't leave in 6 weeks come back”, forcing you to beg him for at least some pain medicine so you can sleep!

You go home to sleep some and then awaken to a major decision. ‘I'm getting another doctor!!!’

And you call a doctor who a friend recommends in the next county and they work you right in. That doctor is very concerned and pats you and says, “Honey we're gonna fix your problem. It's not in your head!”

A week and a half later you've had tests that confirm Multiple Sclerosis (which was the easiest diagnosis the neuro had ever made due to so many lesions showing on my MRI). The spinal really wasn't needed but it was done also.

I was so thankful to hear it was M.S. That may sound odd, but the truth is, of all it could have been, I was thankful it was MS and not something worse. Plus, I was NOT crazy after all! I suddenly knew why I couldn't think of things I was trying to say sometimes, and why I had all the other problems in my past.

I agreed to start on Copaxone injections, then later switched to Rebif, then to Betaseron shots. I was tested again, because for some reason my MS was progressing faster than expected.

I had Solumedrol I.V. every 4 months for exacerbations. (Since I have so many medicine allergies, new meds are really scary for me and for my doctors.) When Tysabri and the other new meds were mentioned I said, "No", because I was not ready to take the risks involved in taking them long term.

Then I discovered a treatment called Low Dose Naltrexone (LDN). I found it when searching on the internet. As I worked in a cardiac unit years ago I understood to be very wary of internet claims for medicines, but this intrigued me and made sense.

After studying it for 2 months I asked my Neurologist to check it out and see what she thought. She wanted to make sure it was safe for me and she studied it too. After 4 months she said she was ready to try the LDN for me, if I still wanted to try it. "YES!" After all, by this stage, I thought what can it hurt?

I was her first patient on it. The second was a nurse from another county who works for a cancer doctor. That doctor was so impressed he put a Pancreatic Cancer patient on it and her blood levels dropped dramatically!!!

Now my doctor calls LDN 'Kristie's Medicine', and says she is getting known as the LDN Doctor here in my home state. She gets calls almost daily for new patients who want to try it.

I've been on it a year now and I have not had a single exacerbation, nor balance problems! My cane and walker have been put away!

Everyone - my family, my friends, my doctors, my pharmacists, and me - are amazed at how well I'm doing! LDN should never be hidden from patients. I talk about it anywhere and everywhere I can to anyone who'll listen!

Later in 2009 I will have my first MRI since starting Naltrexone.

Guess what I did recently ... I played teeter-totter and ran with my grandchildren! It sure feels good to feel young and healthy!

As an update, I recently went for a check up with my neuro (took all of 5 minutes! LOL) I asked how her other patients on LDN are doing and she said pretty good. She also said one male patient developed antibodies to LDN. But he feels better on it than off it, so he decided to keep taking it.

No other meds work for him and when he went off LDN he reverted back to his previous state and was doing worse. I told my neuro about where I read that for some reason some men do better at a lower dose at 2.0 or 2.5. She said she may try that with him to see.

Laura, UK
May 2008 - Multiple Sclerosis
April 2009 – LDN

It started with optic neuritis in my left eye in May 2007. I then got optic neuritis in my right eye in September 2007. My brain MRI in October 2007 was clear.

I started December 2007 with numbness and pins and needles down my right side. In April 2008 I had another MRI, and this time they scanned my neck too. I was found to have two lesions on my brain and 'several' on my neck.

I was given a course of steroids, and diagnosed in May 2008.

In June 2008 I had a severe relapse affecting both legs, which left me unable to walk for a fortnight and off work for 10 weeks. I started Avonex in August 2008.

In October 2008 I had another course of steroids after both feet went completely numb. I continued to have a relapse every 2-3 months. My MS nurse, GP and Neuro are all saying, due to number of relapses, they think I've got a more aggressive form of the disease, but I have not formally been diagnosed with SPMS or PPMS to date.

I continued on Avonex until March 2009. Due to continued regular relapses I was told that Avonex wasn't strong enough for me and that I needed a higher dose of the drug. Therefore, I was started on Rebif. But after only two weeks on Rebif I had to stop as had a bad reaction.

I managed to get LDN prescribed through my GP and started taking it in April 2009. I'm lucky as my father is a GP and it was him that recommended LDN as he has a patient on the drug and knew how much it had benefited her. He spoke to my GP and together we persuaded him to prescribe me.

I'm currently in the middle of another relapse (6 weeks in), again affecting all down my right side and this time there's a new symptom - the terrible 'MS Hug', which is horrible every time I move my neck. Recently, I accepted a further course of steroids after four weeks of no improvement. I stopped taking my LDN on the advice of Dickson's Chemist whilst I was in hospital and for a few days afterwards. I have just started taking LDN again in the last fortnight.

Immediately prior to this last relapse I had a period of about four weeks when I felt really well on the 4.5mg dose of LDN. I remember feeling better than ever, far less tired and no pain.

I think this recent relapse occurred as a result of me catching some sort of virus. I'd been on holiday and my LDN was not delivered before I went away so I had two weeks of no LDN and then caught a virus upon my return from holiday. Rubbish!

I'm still taking my 4.5mg of LDN every night. Unfortunately my MS continues to be really active, the last three weeks has seen my left leg go numb. It's really quite painful, incredibly sensitive to touch. My MS nurse has referred me to the pain clinic and I've

been prescribed some cream made from capsicum chillies. I'm also due to start weekly acupuncture next week.

I've got an appointment arranged with my neurologist in three weeks time. My nurse has suggested that I may be suitable for Tysabri, given that my MS is active and that Avonex didn't reduce my number of attacks. I'm open to discussion regarding treatment options, but am worried about coming off LDN if my neuro recommends Tysabri...

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Laura W, Ireland

2006 – Relapsing Remitting Multiple Sclerosis (RRMS)

January 2008 – LDN

When I was 18 years old I fell in love with a man, and we had our first child when I was 19. We then went on to have a second child when I was 20. We were married that same year and started to plan our future and all of our plans started falling into place.

Then one evening I realised my legs felt numb. It was funny at first, I was laughing and saying pinch me I can't feel it. I genuinely thought it was maybe a trapped nerve in my back as I had been working out pretty hard trying to get back to my pre baby body.

As a week or so went by and the numbness was still there, my family became concerned (I was never one to worry about anything) so for their sanity I went to the doctor. I was pretty shocked when they said I'd have to stay in for testing and I (against doctors advice) left the hospital. I mean I didn't have time for all that. It definitely wasn't anything serious and the stupid doctors were over reacting, right?

After some stern words from my husband I went back that same night and agreed to have some tests done. So, bloods normal, and lumbar puncture normal. Okay, MRI time - not normal. I was later sent to meet a neurologist. To be honest I didn't even know what that was or what they did. I was 21 years old with my whole life ahead of me, and I had 2 very young children. I mean, my life was just starting.

He said we think you have Relapsing Remitting Multiple Sclerosis (RRMS). "Okay", I said, not knowing what that was and without any idea of its seriousness. I was alone in the office and I think he must have seen that I had no clue how serious what he had just said was.

He gave me some information and told me it was very important for me to start treatment immediately. 'MS, what the hell is that?' I thought on my way home. I got home and goggled it. Oh shi*t! So that's what I've got. So I had to decide how I was going to deal with this: I could curl up in my bed and feel sorry for myself and let my family fall apart, or I could fight. I chose to fight it.

So, for the first year I did a lot of research. I had one more episode but thankfully, like the first, it went away by itself. I decided that I would try Interferon, only because it was

the treatment with the least injections (and I hate needles). That, for me, was the worst time in my life that I have ever experienced. Reality hit home. This was serious, and it needed serious treatment. I stopped Interferon after 6 months as I just couldn't continue with it.

I then discovered Dr. Swank and started that diet at the start of 2007. I made myself very physically fit as I believe that the stronger I am, the better I'm able to fight against this thing. After several months of the diet I was feeling much better - not so much fatigue and my hands were less numb, but I still felt that I could be doing more to fight against.

I again started researching treatments. One day while browsing on the Dr. Swank website, I came across one man's story about how he had found a fantastic new medicine that had taken him from being stuck in a wheelchair to walking again. LDN it was called. I immediately started researching it and found lots of great information, all good. Wow! How can I get this, I thought.

I knew I would be wasting my time going back to my neurologist as he is a 'strictly by the book' kind of doctor, and as LDN isn't approved for Relapsing Remitting Multiple Sclerosis. I knew he wouldn't give it to me. I went back to the Dr. Swank website and asked if anyone knew where I could get it in Ireland. I was told to contact my local MS society. I called them and they gave me a number.

Turned out to be the wrong number. Amazingly, when I said, 'May I speak to Dr O' Flaherty', the man on the other end of the phone said sorry you've got the wrong number, but I see a doctor by that name and I could give you his number if you like. The man on the phone was a patient of the doctor I was looking for, and he also had MS, was on the same diet as me, and was taking LDN - and he lived about 10 minutes from my house (oh my god!).

He had only good things to say about LDN. I called the doctor and went to see him that same week, he gave me 4.5mg of LDN and I started that night. I had a little difficulty sleeping for the first few nights but that passed, and it was the one and only side effect – nothing when compared to Interferon.

After a week or so I noticed my mood improving. I had been suffering with ever-changing moods, that is; I could be depressed one minute, happy the next, and then back to depressed. I was also very easily aggravated. Finally, I was getting back to my old self!

No more fatigue, and to my delight, I could play again for hours with my little boys without being exhausted afterwards – and the numbness in my hands was completely gone.

I'm now in my early 20s, and I've been taking LDN for 18 months without any complications.

I have recommended it to many people and I hope and pray that one day it will be available to all MS patients. I truly believe this is the best treatment for all new MS patients.

I'm now in my early 20s, and I've been taking LDN for 18 months without any complications.

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Linda Elsegood, UK

Oct 2000 – Relapsing Remitting Multiple Sclerosis (RRMS)

Oct 2003 – Secondary Progressive (SPMS)

Feb 2004 - RRMS 'in remission'

December 2003 – LDN

Hi! I'm Linda, and after months of being asked, this is the first time I have written my own MS/LDN story.

Perhaps thinking that it was so incredible, I guess I didn't want to tempt Fate, but here goes.

I was born partially deaf, which wasn't all bad. I learnt to lip read. The major operation I needed for this was complicated on a small person so I had to wait until I was at primary school. The operation restored most of my hearing, and my adenoids were removed at the same time. After that I could hear but never at 100% (lip reading skills still come in today sometimes).

I had all the normal childhood diseases, but I was plagued with repeated ear infections and earache and was always on antibiotics. I also had repeated tonsillitis but my doc was reluctant to take them out.

I was young when my periods started and had menstrual problems from onset. I took steroids and other hormone pills almost from day one, until I went on the birth control pill when I married in 1976.

In 1969, at the beginning of my teen years, I had Glandular Fever (Epstein-Barr virus). I was seriously ill and away from school for six months. After that, strange things started to happen to me - trapped nerves here and there, what used to be called 'slipped discs' - you know how the story goes.

Then in my late teens I started to have regular urinary tract infections (UTIs).

Meanwhile, menstrual problems had resulted in my having my first Dilatation & Curettage (D&C) by the time I was 20, and after years of taking antibiotics, they finally took my tonsils out in my early 20s.

I had a stillborn baby boy in January 1979. I gave birth to my eldest daughter in 1980, but then miscarried twins during Easter 1983. My youngest daughter was born in 1985.

In 1998, due to recurring UTIs, a Urologist used a camera to see inside my urinary tract. He told me that I was one of those women for whom it was normal to have infections monthly, and he suggested taking a low dose long-term antibiotic, but I refused. (UTIs are a known MS symptom.)

In 1988 I was diagnosed and treated for cervical cancer. I remember I was also experiencing strange leg weakness at that time but it only lasted a matter of weeks and disappeared. I also had a trapped nerve in my neck that sent electric shocks down my arms to my finger tips (this symptom is called L'hermitte's).

In the ensuing years, I was focussed on being a wife and mother to two beautiful girls. I loved family life and thankfully, my health seemed to 'level out' a bit.

I returned to work and everything, though much busier than before, was still manageable and my health was still stable.

Then, during Christmas 1999 my mother had a serious heart attack and the trauma affected me badly. I was working full time, travelling two and a half hours every day AND running the home.

January 2000 I had a bad bout of flu resulting in two weeks off work. Then followed gastro enteritis. I was already at a low ebb and it took me three weeks to recover. I had a tooth abscess resulting in having a good tooth out.

I apparently slipped a disc causing pins and needles in my right leg. My energy levels were falling rapidly: I was finding it hard to cope and I had to sleep so much.

Easter 2000 I decided I had to break this cycle of ill health. I took a week off work and with my younger daughter Laura, went to Portugal. The day before leaving I felt I had burnt my tongue on the left hand side. I thought I had eaten something like hot melted cheese but could not remember.

Portugal was unbelievably wet, cold and windy: the wind made the left side of my face numb with pins and needles. Back home I went to see my G.P. who thought I had a trapped nerve in my neck. He said I should see a neurologist. The earliest appointment was August.

I worked for three weeks, managing the drive into work, giving one hundred per cent while there, driving home and going straight to bed. In May 2000 my eyesight began to play up. I went to see the optician who said nothing was wrong. Two days later, to my horror, I had developed double-vision. Around this time I also developed cognitive problems.

I had no choice but to listen to my body and stop work in July 2000. Over the next few weeks I lost my balance and the left side of my face, head, tongue and nose were numb with pins and needles. When trying to stand up I either fainted or fell over. I lost one hundred per cent of the hearing in my left ear.

Every day I lost some ability: the pains and fog in my head were terrible. I slept twenty hours a day which was the only saving grace because when I was asleep I felt nothing.

At this point I was really too ill to care. I had a three-day course of IV steroids: These did nothing for me at all. I had an MRI scan, lumber puncture and twenty-eight blood tests. By November 2000 I'd developed optic neuritis and it was feared I might lose my sight and hearing.

Six weeks later I was given another course of IV steroids and I began to feel a little better. Multiple Sclerosis (MS) was then diagnosed. The company doctor at work said I had completely crashed and no one knew if I would ever function properly again.

I spent the next year mainly in bed. I was having an attack every six months or so and it was taking months to get over an attack only to have another. My husband Marcus had to learn, after twenty-six years of marriage, how to iron and cook, both of which he now does very well.

In August 2002 the company doctor gave me a thorough examination and reported back that I was unemployable for the foreseeable future. Being a workaholic I was dumbstruck. Getting back to work was my goal.

In February 2003 I was assessed to go on the interferon trials. In my heart of hearts I didn't want to do this, but my family thought it was the only thing available to help me.

On the Expanded Disability Status Scale (EDSS) I scored 2.5, which I was told was very good. I then had the scale explained. A score of 0 was fit for someone with MS, and a score of 10 meant you were dead! So at forty-six I was a quarter dead. Wonderful.

I started taking Rebif in March 2003. The first liver function test I had was over the acceptable level. The results of each successive test were higher than the last.

I was told to carry on taking it. My health was such that '10' was getting closer all the time. I had to use a wheelchair more and more often, and even bought an electric scooter. The toilet and the bed became my best friends.

In September 2003 my elder daughter Sara got married and I doubted whether I could attend the ceremony. After getting showered and dressed I had so little energy left that all I wanted to do was go back to bed. I did struggle to get there, but came home as soon as I could. This disease didn't hurt just me, it was hurting those I loved too.

By October 2003 I was falling to pieces. I was always in hospital – and the urologist, the gynaecologist, the consultant treating bowels, stomach and liver respectively. My health was such that my GP thought I would only score 6 on the EDSS scale. I saw the neurologist at the end of the month and he thought I had 'progressed' from Relapsing and Remitting to Secondary Progressive. There was nothing more that could be done. No Plan B.

I had had enough of our health system by November 2003. I was so worried over how I would be in a few months that I couldn't even think of the next year. I was deteriorating rapidly and things I could do one week I was unable to do the next. My 'Normal' was becoming weaker and weaker.

I had read a lot about the Low Dose Naltrexone (LDN) treatment and I contacted Dr Lawrence. I stopped Rebif and Provigil and started a special diet plus a regime of vitamins and supplements. I discussed LDN with my GP and she - I had a new one - agreed to monitor me. The results of liver function tests were so high that I was worried what taking Naltrexone would do to me.

In early December 2003 I started LDN, and the results were amazing. By Christmas I was functioning again, and the liver tests were back to normal. I felt like 'me' again (OK, a me with MS) but that didn't matter.

In February 2004 I had to be assessed again on the EDSS scale. The deal when I started the interferon was that I was to be monitored for ten years, even though I had by now stopped taking it. I scored a magnificent 0, even though the neurologist wouldn't recognise that it might have something to do with taking low doses of Naltrexone (although that was all I was taking). It was confirmed that I had reverted to Relapsing and Remitting and was 'in remission'!

Thanks to LDN and Dr Lawrence, I have a life again, and hope for the future. I can plan things AND do them. I founded the LDN Research Trust in May 2004. It is the most exciting thing I have ever done. I am able to give many hours a week to the Trust, helping people to obtain naltrexone and trying to raise funds for a clinical trial of naltrexone for Multiple Sclerosis. A successful clinical trial would result in LDN becoming an accepted treatment for MS and help others.

My head is clear, energy levels up, greater muscle strength. Balance, vision, hearing, bowels and bladder are good.

In March 2005 I was re-assessed on the EDSS scale and achieved another 0. Throughout the last year I have had no relapse. To sum up, I know I have MS and I haven't been cured. I'm not back to the old me, but if I can remain like I am now (a major improvement in symptoms and no further progression) I will be more than happy.

Update - July 2008: 1999 started off being a good year.... My husband Marcus had been made redundant after 18 years working for Anglia TV but was managing well in the freelance 'sound' world.

My elder daughter Sara was happy living away from home.

My younger Laura was 14, and had asked to go to boarding school to take her GCSEs to cut down on travelling, she wanted to spend the extra time studying.

As for me, I had the job I wanted working for the Virgin One Account (banking). The family were happy and well and life was good.

Until... I came home from work the Monday before Christmas, my friend was already there cutting Marcus's hair and she was telling me to get my coat off and my hair washed as she was almost ready to cut mine.

Then something happened that had never happened before, my father called me, he doesn't hear well and hates talking on the phone. He said "Your Mum's had a heart attack and they are now taking her to hospital."

That statement was to change all our lives forever!

I'm an only child so had no siblings to share this difficult time with. I arrived at the hospital about 8.30 pm, mum was in ICU. I was too scared and frightened to sleep for two nights, I thought if I slept mum would slip away. I was very tired, stressed and worried, I also had the added worry of my father who is wheelchair-bound. Little did I know what the trauma would do to me.

Mum survived, even though a third of her heart died and they both had to come live with me for a while. Mum's heart attack was due to hereditary high cholesterol; this was when I found out my cholesterol level was 9.7, which resulted in me having to take pills daily.

I carried on working, feeling so very tired; the 60-90 minute drive to work every day was killing me. On my days off I was cleaning, doing food shopping, and other housework. My life was work, cooking, cleaning and spending as much time as I could in bed.

Between Christmas 1999 and Easter 2000, I had a tooth abscess that resulted in having the tooth removed, a slipped disc, flu and gastroenteritis. I had never felt so ill in all my life; I felt I couldn't cope anymore. I said to Marcus I wanted to go away on holiday and come back a new woman. He said he was unable to take any time off, so Laura and I went to Portugal for a week.

The day before we left I took Laura shopping for shorts and T Shirts. I had an odd feeling on the left hand side of my tongue, it felt like I had eaten food that was too hot and had burnt my tongue. I spent some time trying to remember what I had eaten that might have caused this, but gave up and carried on.

Portugal was very wet, cold and windy. We had the choice of sitting in the apartment or making the most of being there-going out and getting wet. I thought it very strange that the cold and the wind were making the left side of my face numb with pins and needles.

When we got home, I returned to work and made an appointment to see my doctor. After a week away I was feeling even worse than when I left. I was giving work 100% but was collapsing in bed as soon as I got home, and I stayed there until I had to have a shower and go back to work.

My GP thought I should see a Neurologist as he was unsure what was wrong with me. I also had to rethink working, as I simply couldn't manage the hours. It was agreed that I could work part-time and have 3 days off a week. I managed to do this for a few weeks until I developed double vision, at which point I had to listen to my body, stop work and rest.

All I wanted to do was sleep; I thought it was best to let my body heal; not knowing that short-term would turn out to be about a year.

I now had the problem of not working, hence not getting paid. We had Laura's school fees to pay on one salary. Marcus worked out we could afford for me to have 2 months off work. It was fortunate that at the time we didn't know I was never to return.

I was sleeping more and more, going to the toilet more often. The numbness was spreading from my face and down my left side. The hearing went in my left ear, muscles were twitching, and my thighs were burning as if sun burnt. Balance was a thing of the past, fainting and vertigo was becoming the norm. Trying to get to sleep at night my legs would thrash about and when I tried to get out of bed they felt as if they were made of rubber, I would bob up and down and more often than not I would fall over. I became a master of falling asleep either while talking myself or while other people were talking to me.

Marcus at this point of our married life hadn't learnt to cook, clean or use the washing machine, and the iron was a mystery to him. He had a crash-course and had to learn quickly. Life wasn't easy for him either, when he works he's away and he couldn't afford to stay at home looking after me.

Each day something else in my body didn't work properly, I was having really bad problems with "exploding" bowels. I was unable to put a cup to my lips, I was walking holding on to furniture but was unable to go through my front door without help, let alone shower.

My parents would come over on Saturdays to visit me, mum would sit on the bed and talk to me and I would alternate between sleeping and awake. Sometimes she would try and help me get up and sit in the lounge but it took so much out of me that she would have to help me back into bed. I was sleeping 20 hours out of 24, but it was a blessing as I felt nothing while asleep. I wasn't living I was surviving.

At this point it was killing me to see the sorrow in people's eyes when they looked at me. I knew they all wanted to help me and felt inadequate, as did my doctor.

The pains I was experiencing in my head slowly got worse and unbearable. There was a trade off, I could either suffer the pain or take strong painkillers and feel very nauseous.

I finally saw a Neurologist who thought I had either, had a mild stroke, a tropical disease, brain tumour or MS. I didn't like any of these choices to be honest but had to wait for the results of a lumbar puncture, MRI, evoked-potential tests and 28 blood tests.

While I waited for the results I was given a 3 days course of IV steroids. Six weeks later my condition deteriorated to the extent the Neurologist was concerned that I would lose my sight and hearing completely and recommended another 3-day course of IV steroids, even though the first course did nothing. I then developed optic neuritis. It was after this Relapsing and Remitting MS was diagnosed.

Marcus was away working, Laura was at school, my next-door neighbour was keeping an eye on me and the doctor came out to see me. He let himself in, brought me some more painkillers and fetched me a glass of water. I asked him when he thought I would start to feel better, and he replied; "If you were going to, you would have by now" and then he left. I felt so ill, I couldn't do anything let alone achieve anything and I was in a lot of pain. I couldn't bear what all this was doing to my family, and our friends had stopped visiting.

I looked at the painkillers and thought if I were to end it all, it would be a shock to everyone, but I felt they would understand and eventually life would carry on for them. I then had to think it through, things like, who would be the person to find me? It would have been Laura, how could I do this to a 15 year old. The answer was simple. I couldn't do it. It was then that I decided I would show my doctor he was wrong and that I would beat this MS if it killed me!!!

The biggest problem I had was cognitive problems, suddenly I couldn't retrieve my vocabulary or if I did it was very slow and often I said totally the wrong thing and thought I had said it correctly. I feared I was losing my mind. I spoke slowly and it was often rubbish!

I was having a relapse every 6 months, and it was taking about 4 months to start to recover from a relapse only to have another start. I went for an assessment at the interferon clinic and started on Rebif. This was something I didn't want to do but my family thought it was the only thing available to help me. My liver-function tests hit the roof on Rebif, but even so, my Neurologist wanted me to stay on it. He said it would settle down, but it never did.

It was during this period Sara brought home Darren, her future husband. We didn't know they were coming and I managed to drag myself out of bed but couldn't manage to get dressed. He must have wondered what kind of family she came from.

I was spending a lot of time at the hospital seeing a variety of consultants, for my bowels, stomach, and bladder. I had cervical cancer when I was 32, around the time of the first MS symptoms, had a series of follow-up operations and was told I needed another but they couldn't operate again until I had been free of steroids for 6 months. This was extra stress I didn't need. I then became type 2 diabetic, diet controlled.

I went for a medical assessment with my company doctor, who after examining me announced that I was "unemployable for the foreseeable future". For a workaholic it was devastating news, the thought of going back to work one day had been keeping me going.

Sara and Darren planned to get married September 2003, I managed to get showered and dressed and then needed to go back to bed and sleep. I told Marcus I couldn't go to the wedding but for him my staying at home was not an option. We went and I only managed due to the fact I used my electric scooter. As soon as the speeches were over we left, which was upsetting for all involved.

Though my last relapse was back in May 2002, my MS had been progressing to the extent the strength in my left leg went, and it was at that point I was told by my Neurologist that I was Secondary Progressive and there was nothing more that could be done for me. So, no plan B: We would see about that.

When I needed the toilet I would struggle to get to the PC and I would then sit for a short time, squinting with one eye and try to find out what other people were taking for MS. I eventually, after a few weeks, found LDN and people already taking it with great results.

I printed everything and took it to my new doctor, the original one had retired. I now have a great young lady that could have been a school friend of Sara's! I asked her to read the documents and tell me what she thought and could she prescribe it. I went back two weeks later and she said the partners in the practice wouldn't allow her to prescribe LDN for me, but she said if I got it privately she would be more than happy to monitor me so that is what we did.

I contacted Dr Bob Lawrence who suggested that I change my diet, take supplements and start LDN. I started LDN 3rd December 2003. After just three weeks things were improving and I started to feel like the old me again. This continued for about two years and then I stabilised.

Before starting Rebif in March 2003 I had a 2.5 score on the EDSS scale. Three months after starting LDN in December 2003 it went to 0, where it still is today.

Ok, I know I have MS but life is good. I can set targets and achieve them; I once again have goals and aims for the future. I'm not troubled by my old symptoms apart from fatigue and hot weather.

After my success with LDN I wanted everyone to know about it. I formed the LDN Research Trust in May 2004 and I spent all my time trying to help other people who are in the same place I used to be in, whilst trying to raise funds for LDN clinical trials.

My biggest blessing is having my grandson Leo; I can be the grandmother to him that my mum was to my girls, something that wouldn't have been possible before LDN.

Life isn't the same as 1999 for any of us, things have changed but then nothing stays the same in life for anyone. I now am not afraid of what the future holds....

Update – July 2009: The only thing that has changed is that I was very ill with diabetes at Christmas. I have Type 2 Diabetes and I was no longer able to control it with diet. I had to start taking a slow release metformin. I also had to loose weight so I halved my meals and have lost 40 lbs since Christmas!

MS wise, I had flu just before Christmas, which was the cause of my diabetes playing up and my MS symptoms starting to return (in the form of chronic fatigue and leg weakness). Once everything settled down, so did the MS symptoms and I'm the same now as I was this time last year :)

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Lisa C, UK
January 2009 - Multiple Sclerosis
February 2009 - LDN

This is my story about how I came to be taking LDN and how it has affected me. In January of this year, 2009, I woke up one day and noticed that my feet felt kind of funny on the floor, not numb or tingly, just a little funny. I thought I was imagining it. Later that day I realized that I couldn't feel my bottom properly when I sat down (saddle anaesthesia).

This worried me a lot as I work as a physiotherapist and new this was a red flag and could have serious implications, that is; that there may be some sort of pathology occurring which could potentially reduce bladder and bowel function.

Later that evening, these symptoms had not subsided and so I decided to go to Accident and Emergency to make sure there was nothing sinister going on.

I waited 3 hours in A&E... until 4am to be seen and told there was nothing wrong with me and I may have a virus but it would clear up and I would be fine. I went home.

At this point I couldn't feel any of my feet properly. The numbness was worsening and spreading. I managed to get an urgent appointment with a consultant physiotherapist where I worked the following day.

By the time I saw the physiotherapist, the numbness was spreading up my legs as far as my knees and parts of my thighs, symmetrically. He was unsure what was causing it since it did not fit anything he knew. MS came to mind, but symptoms for this are not usually symmetrical. He felt I required an urgent MRI scan of my lower back and wrote a letter to my GP requesting this.

The following day I saw my GP with the letter from the physio, he felt I needed to see a neurologist urgently as I may have a condition called Transverse Myelitis (TM). I was referred to my local hospital where the urgent waiting list was 9 weeks long. My numbness at this point was still progressing and I had a gripping sensation around my calves and thighs. The proprioception in my toes was gone, i.e., they felt like they were all twisted and contorted but they were obviously in the correct position.

I read up on Transverse Myelitis and realised how serious this could be. The cause is not really known but it is felt to be caused by a virus, which in turn triggers inflammation and demyelination of a section of your spinal cord. All function is then lost below this level to some degree. This can mean in many cases complete loss of all feeling and strength and even the requirement of going on a ventilator to support breathing. I was so scared. It was like living a nightmare.

Each day the numbness would progress and I didn't know when it would stop. Would I become incontinent, would I be in a wheelchair and never walk again, would I still be able to breathe. I tried to book a neurology appointment online with the NHS's online booking facility, only to be told the system had locked me out just as I tried to book it online, as you are supposed to. I then had to wait until the following day for the system to unlock itself, but apparently, this particular appointment couldn't be booked online, and I was told I would have to ring up to do this, which I did.

I was so stressed and angry. I decided to book a private appointment and lost faith in the NHS there and then, and to be honest... this faith has never returned.

I managed to get an appointment at a local private hospital 2 days later. I attended this and had a thorough examination. I was given a probable diagnosis of Transverse Myelitis and told to rest as much as I could to get the best possible outcome. An MRI scan was arranged which I also had to pay for since the NHS waiting time was another month minimum, and that was if he pushed it. By this time it would have been too late for any treatment.

Possible treatment consists of IV steroids, but generally these are only beneficial when used within the first month. I organized the scan myself at a private hospital I used to work in. I had this within 3 days. I then had the results 2 days after this. These were inconclusive. They showed a lesion on my lumbar spine, a large one in my neck and a few in my brain stem, indicative of Multiple Sclerosis (MS).

By this time my thoughts had moved from 'please, I don't want transverse myelitis' to 'please let it be TM and not MS'. I didn't have sufficient lesions on my brain to confirm as MS, but on the other hand, TM spares the brain - you get no brain lesions. Therefore, a lumbar puncture was arranged. I had this the following week with a barrage of blood tests.

During this time my numbness had progressed to chest level. I had a very tight girdle like sensation around my waist that moved up to chest level. At times this was so tight I felt like I couldn't breathe properly. I had strange muscle spasms all around my rib cage that felt like big worms wriggling around my back. I had muscle spasms on my chest muscles. These often woke me and made me catch my breath. I had constant vibrating down my spine.

Whenever I woke in the morning I never wanted to move, as just for a few seconds, I felt normal. I had no sensations, then as soon as I moved just a little, just once, all the sensations returned. I felt like I had constant water being flushed around my legs. Although my legs were numb, if anything sharp touched them, they were so hypersensitive it felt like someone had pushed pins into me.

One day I realized I wasn't aware any more if I needed the toilet - I just had no sensation at all, so I took medication to make me go to the toilet.

I had so much fatigue and constant exhaustion that sometimes I didn't have the energy to speak. Going downstairs once a day exhausted me for that day and the next. I had to sleep for the majority of every day. I couldn't look after my daughter at all, not even get her dressed, so she had to stay with her grandparents in Essex at the other end of the country. This was truly terrible. I couldn't move properly, feel anything, keep awake more than a few hours, be a proper wife and I couldn't be a mother at all.

My brain had become like a fog, my memory was impaired, concentration had gone - I felt like I was thinking through a cloud. How could I ever work again?

I used to put a really tight belt around my waist so I could feel the crushing sensation less and enable me to forget about it enough to get some sleep at night.

When I rested I would get little flickers of muscle spasms all over my body, like little twitches and aching and strong jumping in my left thigh.

My legs felt like I was walking on planks of wood that did not belong to me and when I lay in bed I felt like I was floating in space as I couldn't feel the pressure of the bed on my body.

I returned for the results of all my tests. My neurologist at that time was very lovely and read me very well. I knew for this to be MS they were looking for something called Oligoclonal bands in my lumbar puncture. Right in front of where I sat was a bright yellow post-it note with positive for oligoclonal bands written on it. The consultant kept flicking this up so I could read it. I guess he was preparing me.

All the other tests were negative. But, this still wasn't a conclusive diagnosis. For a proper diagnosis of MS you have to have a second relapse. All he could tell me was it was probably MS. So there was no treatment they could offer me at this point. I just had to wait and see what happened.

I discussed with him some research I had read on the internet. This was about people in my situation with probable MS, and that if they receive the Disease Modifying drugs for MS at this point, they had much less chance of going on to get clinically definite MS. I asked him if I could have this treatment so I wasn't left in this limbo situation. He

agreed to refer me, but said I probably wouldn't get accepted for this as I didn't fit the criteria, but he would try.

I was accepted to see the MS neurologist at my local University NHS Hospital, and I was sent an appointment to see him within 2 months.

Whilst resting at home and awaiting for this appointment, I spent a lot of time on the internet, determined to do all I could to help myself get the best outcome possible. I joined the MS Society forum and started reading about supplements that can help, eg vitamin D and Omega 3's etc. I asked for advice on the MS society Forum. A very kind man suggested I read the information on LDN research; which I did. This was when I discovered LDN.

I had already read about the usual NHS treatments for MS that require sometimes daily injections. These drugs only at best reduce relapses by 30%. They mostly suppress your immune system which obviously isn't good and have many bad side effects such as flu like symptoms, infections at the injection sites in very large numbers of people, and they do not help address the chronic fatigue that I was experiencing. I have a 3 year old daughter, a busy job as a physiotherapist and have only been married for 3 years. I just had to get better from this and find something to help me.

I asked a lot of people a lot of questions on the internet regarding LDN and their experiences, not to mention the Dr who prescribes me my LDN who gave me a huge amount of information. I even asked a friend that worked for a big pharmaceutical company about what she thought, and if she'd got any inside information on the drug side of things. I was scared and very hesitant to take LDN as it hasn't been clinically trailed for MS. Also, I didn't have a confirmed diagnosis, and my neurologist wouldn't prescribe it for me.

During this time, I started to have new symptoms; tingling in my face and lower jaw and occasionally around the top of my head. I knew this meant it was likely to be MS. Transverse Myelitis does not give facial symptoms unless you have a very high lesion on your neck, which I didn't.

I then started to get numbness above my chest and down my arms. I was now afraid I was going to lose feeling in my hands as well. This would have made functioning at all very difficult. At this point I decided to take the plunge. My husband was so supportive, that for my first dose, he took it first!

That was 6 months ago now, and I haven't looked back since.

Within a few weeks of taking the LDN my energy levels gradually returned. I had to very slowly increase my dosage as I am very sensitive to medication and so I started on an extremely low dose. Every time I increased the dose I felt better. My brain fog, concentration and memory all cleared within 2 weeks. I actually feel like my concentration is better than before my illness.

My energy levels are fantastic and I'm living my life normally again. Yes I have to be a little careful not to overdo it, but to be honest I have more energy than my husband!

As for my symptoms, they initially worsened but only for a few days. I was told to expect this. Then, they all very gradually disappeared. The Girdle like sensation went first. Then my sensation began to return in the same order it had first developed.

I now have just a tiny bit of numbness in one finger, slightly reduced sensation on both big toes and a bit of tingling in my face but only when I'm tired or stressed. I get the occasional tingling on my thighs when I have done some exercise.

I attended my NHS consultant appointment and I discussed LDN with him. He completely dismissed it, would not look at me, or talk about it at all. He arranged some repeat MRI scans to look for any new lesions that would give me a definite diagnosis. There was a 3 month wait for this.

I had the results to these only a few days ago. I have no new lesions, and in fact one of the brain lesions has gone, which is great. I was told by my neurologist that I wouldn't go a long time without a relapse given what my lesions were like.

But it is not plain sailing from here. The large lesion in my neck, which resulted in my numbness, still has some inflammation around it. This hasn't properly settled down yet. There is a risk this can all happen again, if this lesion reactivates.

I take many supplements alongside my LDN to help me, and I will never stop taking the LDN. All my lesions indicate MS, and I believe LDN has helped my lesions.

Well, touch wood, I haven't had any relapses so far. My energy levels are fantastic. I even rode the Tissington trail the other week! My thinking, memory and concentration are better than ever and I feel great in myself. These are all certainly down to the LDN.

This drug needs trialling so that it can be available to all those people that need it so much.

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LS – Anon, UK
2007 - Relapsing Remitting Multiple Sclerosis (RRMS)
October 2008 - LDN

I'm a 50 year old female with Relapsing Remitting Multiple Sclerosis, and I was diagnosed some 2 years ago.

The diagnosis itself was a big shock and was not helped by poor communication and lack of support from a variety of health professionals.

The original diagnosis did not include or recommend any treatment as 'it was not necessary and I would not want to inject myself and have to cope with awful side effects'.

However, I am a confident person, literate and totally supported by a lovely husband. I am also a full-time Director in a College of Further and Higher Education, which include specific responsibilities for people with learning difficulties and disabilities.

This position also gives me full access to all possible literature and a search of all unbiased European research quickly made me realise that I should be prescribed medication, and as soon as possible. As a result I have been on Copaxone for more than a year now and, despite the assertions of my consultant, get on with this very well.

I keep up to date with news from the MS world, and my husband found an article in the Daily Mail about the Welsh GP who has MS and takes LDN. Further research into LDN convinced me that this had been well-tried and tested, was relatively cheap, and could help to address my energy levels and my stiff limbs in the mornings.

I got the address of an LDN prescribing consultant from the LDN Research Trust, made a private appointment, and have been taking LDN for more than 10 months

Since taking LDN, I've had no stiffness in the morning, higher levels of energy, improved circulation, and have been feeling good all-round! I've had no side effects at all, and I continue to work full-time in my role.

The response from my consultant is that I am wasting my money on "quack medication". Despite this assertion, I continue taking LDN and have recommended it to others. A colleague of mine has been taking it for more than 4 months now. She also has Relapsing Remitting MS, and she reports that the biggest change is that her feeling of depression has been lifted and she feels positive about life again - worth every penny as far as I am concerned.

I would like to conclude with a plea that GPs take LDN on board and prescribe it and that other health professionals at least respect the LDN choice their patients make.

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Mark S, UK
February 2009 - Multiple Sclerosis
May 2009 - LDN

I'm still under 40 years old. Before taking LDN, Multiple Sclerosis was causing many problems for me, and I'd had to stop working. Tiredness, numbness, incontinence, double vision and spasticity were all getting worse and making life very difficult.

I was deteriorating pretty quickly, and frightened of needing a stick or a wheelchair in the near future. I couldn't walk very far at all. If I could manage a day's walk, it would mean spending the next day in bed. My active life was gone, life was closing in on me, and I was very upset.

The LDN Research Trust helped me find a doctor willing to prescribe Low Dose Naltrexone, and after only two months my symptoms are improving so much that last week I climbed Ben Nevis, and next week I'm going back to work!

I believe LDN is giving me back what Multiple Sclerosis was taking away, and I'm not as worried about the future now. I can't thank the LDN Research trust enough for helping me.

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Mark W, UK
early 2006 - Multiple Sclerosis
January 2007 - LDN

The first time I noticed something was wrong was one evening when I got in the bath. The water felt warmer on one foot than the other and when drying myself I found a numb patch around my right shoulder. I thought it was a bit odd and made an appointment with my GP but he was not too worried. He said it was probably a trapped nerve but to come back if anything got worse.

Things did get worse over the following months with a whole array of symptoms such as losing my sense of taste, more numbness, pins and needles in my hands, feet and tongue and the final straw was losing strength in my right leg until it became practically useless.

Although my GP did not mention MS to me, he had sussed it out and said I needed to see a neurologist. The wait for that on the NHS was around three months, which was unacceptable. Even going private would see me having to wait a month but I needed help ASAP.

Being the good man he is, my GP at the time (he's now retired) recommended I get myself checked into hospital and I would be seen by a neuro in a matter of days. It was 'off the record' advice but the best thing he could have done in my eyes.

After a battery of tests I was told it was suspected Multiple Sclerosis. A bit of a bombshell, but at least now I knew what it was and could try and deal with it. I'm fortunate enough to have a wonderful, supportive wife who was/is with me all the way, for which I'm eternally grateful. I also had other family and friends around which all helped.

The steroids I was given slowly brought the strength back into my leg and other symptoms subsided. Within a couple of months I was back at work, but that was far from the end of it. Sensory symptoms seemed to come and go as they pleased so I looked forward to my neuro appointment for some answers and treatment. I got neither!

I left the appointment feeling let down, and with another appointment made for a year's time, I was not happy. It was a couple of months after that when I had another major relapse with the whole left side going numb and the leg was getting weak again. This MS thing was now pissing me off, and I needed to know all I could about it and what could be done so I embarked on a mission to learn all I could.

The internet is a great tool and if you can avoid all the rubbish on there, then there are some very helpful sites.

I was looking into what drugs were available and reading patients own first hand opinions on them when I came across something called LDN (Low Dose Naltrexone). The reviews this drug was receiving were too good to be true, so at first I was sceptical, but I read on. The more I read into LDN, the clearer the picture became, and I felt a relief that there was something that worked, and a degree of anger about the situation surrounding the drug which prevents many GPs from prescribing it. Red tape and profit should never come before health, but it does!

I contacted Dr Lawrence and made more progress in that first phone conversation than I had since I was first diagnosed. Pretty soon, my first batch of LDN arrived and the affects were immediate. I took my first capsule that evening and felt like a new man come the morning. Some of the numbness was still there but it was definitely going.

Over the following few weeks, along with support from Dr Lawrence, I moved from 3mg of LDN to 4.5mg and I reached a point where, for the first time in a year, I was symptom-free. That was two and a half years ago now, and apart from a couple of hiccups that I can put down to personal stresses, I'm symptom free to this day.

To say that LDN is the best thing to happen for MS is a gross understatement, but more needs to be done to get this drug available to everyone on the NHS. It's thanks to wonderful people like Dr Lawrence who first brought LDN to the UK and Linda Elsegood who runs the LDN Research Trust that LDN has got where it is now and both deserve a big 'Thank You' for the work they are doing. With support, I'm sure LDN will get to where it needs to be.

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Mary B, UK
August 2005 - Multiple Sclerosis
2004 - LDN

Since starting LDN five years ago I haven't looked back.

Within two days of taking 4.5mg LDN, my fatigue vanished and my energy levels improved steadily.

Despite numerous knee surgeries and treatment for breast cancer, I haven't had any relapses or any noticeable deterioration in symptoms. I no longer see the Neurologist, and the MS nurse is very impressed with the stability of my condition over the past few years.

At times the LDN capsules have been difficult to access but the chemist, Dickson's, has been brilliant.

I would recommend anyone with MS to give LDN a try, because if it works for you it gives you most of you life back.

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Mary L, UK
1967 - Multiple Sclerosis
July 2004 - LDN

LDN and Multiple Sclerosis (MS) - Our Experience

My wife has had MS for at least 42 years and it progressed steadily over that period.

She was initially diagnosed as having Epilepsy a year after our marriage in the early 60s (quite traumatic in itself). Then she was diagnosed as having MS as well! About 10 years ago they said the initial diagnosis was wrong (there were no MRI scans in those days!)

She lost the use of her legs and has been in a wheelchair for the last 25 years, since 1984. She'd been in constant pain for about 30 years and had been using a TENS to alleviate the pain. Ages ago she lost the use of her left hand (she was originally left handed) and had progressed to the stage that she could no longer feed herself. She was incontinent and had various other problems.

Throughout, my wife has remained cheerful and chatty. She was in the process of losing the use of her right hand and would then have been unable to even hold a drink in her hand. We were rather worried to say the least, and then some friends told us about LDN. They said it had worked for them, and my wife said, "I want some of that!"

I wouldn't let her rush into it until we had discussed it with our doctor. He was reluctant to give us a prescription at first but I was insistent, and after discussing it with two colleagues he agreed to give us a Private Prescription. That was in July 2004.

Our doctor's reluctance is easily explained by the fact that the NHS makes it quite clear that it is the doctor's total responsibility if he prescribes 'off-licence'. We started her on a 3mg dose because that was the recommended starting dose at the time.

We played around with the dose at first and ended up on a 2mg dose. We're still trying to get the dose right, and this appears to be the one factor that needs to be resolved with LDN!

My wife got slightly worse at first but within days the pain in her legs had gone completely, her fatigue was greatly reduced, and spasm had been decreased to almost nothing. She still suffers from stiffness in her legs and sleeplessness (both problems, but not life-threatening).

Importantly, she can now hold a mug again and drink by herself - that small bit of independence is important! We had hoped for more improvements but did not expect any. We mainly hoped that there would be no further progression.

In fact, my wife's condition has slowly deteriorated over the 5 years she has been on LDN, but she is still better than when she first started on LDN - and Dr Bihari only ever claimed LDN would stop the progression. It has been £1.00 per day very well spent!!

In fact, she has also tried AIMSPRO which claims to improve her condition. It did for a while, but any infection stops it working, so that is on hold for a while as she keeps having bladder infections, and she is back on the LDN.

All along we have been determined not to allow MS to rule our lives! It does of course, but my wife has been brilliant at keeping going. We have flown to South Africa (last time in 2007), Turkey, have travelled by ferry to France where a friend has a place we're able to cope with and which we hope they won't sell, have flown by helicopter to the Isles of Scilly, and have driven to various places in Britain.

It gets more difficult each year, but our motto is 'you only live once and a long time dead!!!'

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Maurey G, USA **July 2007 – Multiple Sclerosis** **August 2007 – LDN**

I was diagnosed with MS in July '07. Looking back before my major episode, I had strong symptoms that I denied for 5 years or so. In July 2007 I couldn't climb steps, I dragged my legs to get around, had no central vision in one eye, cried for no reason, had slurred speech and couldn't find the words for my thoughts, and I was so dizzy I walked into walls.

I started LDN in August '07, right after receiving my diagnosis. The first month I took 3mg, and I've been taking 4.5mg ever since. The greatest improvement in my symptoms occurred in the first 30 days. Improvement is slower now, so I keep a diary and check in with myself every 3 months. I haven't been disappointed yet. Once in a while if my legs feel stiff I drop back to 3 mg for a day.

I follow most diet and supplement recommendations related to my condition. I also have high cholesterol but my new diet has reduced my bad cholesterol by 20 points and increased my good by 7 – a nice side benefit.

I have 80% of my leg function back, no more dizzy spells, and no more speech problems. I have some loss of color vision in one eye, but I can see. My MS taps me on the shoulder every now and then, but I no longer think about it 24x7. I continue to work on my balance and leg strength with various activities.

At my 6-month check up with the same neurologist, he gave me a lecture on LDN not being FDA approved and strongly recommended Rebif to slow the progression. I asked him how he could possibly recommend expensive painful injections when I'm doing so well on LDN.

My LDN was prescribed by my GP who said "Why not? It makes perfect sense, won't hurt you, and the CRAB drugs are limited in their effectiveness."

My Neuro report came in the mail. He must have done some thinking after our visit. It reads, "The patient has done quite well since I saw her in July. She has had no attacks of multiple sclerosis. She takes low dose Naltrexone. She gets that medication through her primary care provider. She is aware that there is no evidence that this is helpful in multiple sclerosis. She is not interested in going on Interferon medication at this time and I do not think that it is necessary at this point either. It may turn out that she has benign multiple sclerosis."

I say, that if it is benign, it's only because of LDN, diet and exercise. I do believe attitude plays a big role. I'm putting a son through college and have 5 horses that must be fed and cared for. I cannot be disabled and will find the way.

That's my story and I'm sticking to it.

Update - July 2008: I'm still doing very well on LDN - no further progression or attacks, no medical information to report. Still following the same routine, LDN, supplements and exercise. No episodes, no progression, slow but steady improvement in leg strength and balance. Tolerating the heat of summer much better than last year.

Update - July 2009: 2yrs on LDN and I'm still firmly committed to LDN. No exacerbations - one very tired day after extreme exercise in high heat. In general, I'm able to handle heat much better than a year ago. Frustrated by a plateau in improvement, I've been seeing an acupuncturist/Chinese herbalist who is doing FCT testing and therapy for Lyme, Babesia and mercury poisoning. I believe it has sparked some improvement.

I'll see my neurologist on July 31 for my first repeat MRI.

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Michael G, UK
1983 - Multiple Sclerosis
1st January 2009 - LDN

I have had MS since early 1983 but I was not aware of it until 1995 when I had a full medical in order to secure a mortgage.

Until four or five years ago it was relatively easy to live with and had very little effect on my quality of life. Then my balance went, I lost a lot of function in my fingers, I started to get spasms, and strange sensations in my legs (which I now know is called paraesthesia).

I continued coping reasonably well until 2008 when things went really downhill. I had to give up work in August 2008 due to losing function in my legs so much, that in November 2008 I got a wheelchair because I could no longer walk more than a few yards - and that was very slowly and carefully with the aid of a walking stick.

My legs felt like permanent lead weights. I was getting faecal urgency five or six times a week, and it was taking me ten minutes to get out of bed and stand up in the morning. My strength was failing fast, I was permanently tired and mostly in bed well before 9pm.

I stopped going out and I would not go on holiday because I got to the stage where everything was beyond me.

My GP arranged for a physiotherapist and an occupational therapist to visit me, but also told me that there was nothing that could be done about the particular type of MS that I had. However, when the occupational therapist came she told me of a patient of hers who had made a substantial recovery using Low Dose Naltrexone.

After researching LDN on the web I approached my GP (my original GP had just retired) and after she had done her own research she agreed to prescribe it for me despite the fact that it has not been approved by NICE.

I started taking LDN on January 1st this year, beginning at just 1.5ml each evening. After two months I, and my family, noticed very small improvements in lots of areas. I increased my daily dose to 2ml (which I am still on) and after another two or three months there were further small improvements, the most noticeable being that faecal urgencies are now only two or three times a month. My balance is better although still far from good, my strength has returned a little, I have more control of my digits and I'm told that my speech has improved.

My legs still feel like ton weights all the time, and walking and balancing is still very difficult and uncomfortable, and I still tire quickly - but having previously been told nothing could be done for me, I feel that LDN has helped me back towards a better quality of life.

It's now September 2009, and I've been taking LDN for 8 months, still at 2ml each night.

I have just received my first private prescription via online ordering - E-Med - and they were very efficient.

I've also been trying to obtain my LDN as an NHS prescription rather than a private prescription to get the cost down, so I submitted the required 14 page form, duly completed by my consultant physician.

My case went before the PCT, who suddenly decided they could not make the decision! It then went before the Drugs and Therapeutic Committee at the N & N Hospital who said they could do nothing as my consultant was not the person who

should have filled in the form! The form is now with my GP, who I will be contacting shortly.

My condition has been a little erratic of late - I put it down to this stress - is this possible?

If, once my case is heard, I am still not allowed an NHS prescription I intend to write to our local MP.

Michelle X, UK
April 2004 – Multiple Sclerosis
Sept 2006 - LDN

I had my first MS attack just before I turned 20.

I went into Oldchurch Neurology Unit for 6 days for tests.

I recovered completely, and MS wasn't diagnosed at the time. All they said was that the results from the lumbar puncture showed a trace of a virus in the spinal fluid.

My life then went on as normal. I had 2 children and it wasn't until my early thirties that I started to have problems, which I now know was leading to the Multiple Sclerosis diagnosis. I slipped on a cliff path abroad and tore a ligament in my ankle... this led to various operations and complications, but they still never mentioned possible MS, even though I was experiencing classic symptoms such as walking quite badly. My walking had deteriorated, and I couldn't walk long without pain.

I booked a routine optician appointment in April 2004 because I'd started having problems reading small print. From there things moved really fast downhill, and I was offered an MRI scan, which showed undoubtedly that I had MS.

It was shortly after this that I began using a crutch to assist my walking, and joined a local MS therapy group to make sure I was doing the right exercises, etc.

They offered me Rebif as a treatment. I was on Rebif for a year before I started getting warning signs that it wasn't helping me but making me feel worse.

Then one day, after what had become a regular high dose injection of steroids to help me recover from the Rebif, I was walking upstairs 1 day (comfortably) when I was hit by the most awful pain. It turned out I HAD BROKEN MY LEG IN TWO PLACES JUST WALKING UP THE STAIRS!!!!!!

Having never broken a bone before, I started to question why... and I found out that brittle bones was a by-product of repeated use of steroids. I resolved there and then to seek another treatment.

I went to my Neurologist to ask his advice, but he was totally unhelpful and told me I was lucky to be on Rebif... and I just had to accept that my MS was progressing...

I'd heard a bit about LDN from various MS sources, so I asked him what he thought about it. He said, "Try it if you want, but you won't get it prescribed round here." He then told me of the dangers of unlicensed treatments... all of this though, he said in a sneering 'I know best' way. I was mortified at his lack of support. I then tried my GP... same story there!

So with no help from my Neurologist, I decided to ask anyone I could find with MS if they were using LDN. I got lots of emails back - with lots of really positive effects. I then made what was the hardest decision of my life, and that was to ditch the Rebif (against my specialists and GP's advice), and pay privately for an online prescription and liquid LDN from Dickson's Pharmacy in Glasgow. The Rebif had started having such bad effects I felt I had to.

I began LDN in September 2006, and within a few weeks felt better than I had for ages ... I had more energy and I just felt more alive. People commented on how much better I looked.

I was still working full time, but it became less of a struggle on LDN.

Then one day, quite suddenly, I realised I hadn't been having to have a 2 hour sleep as soon as I got home from work!!! I had hoped it would reverse the damage to my right foot... but that was probably too much to ask. I really do believe that if I'd been diagnosed sooner and found LDN sooner, I'd have been a whole lot better off.

I've been on LDN now for nearly 3 years and I'm really happy with what it's done for me. I wouldn't even like to imagine where I'd be now if I'd stayed on Rebif. For the last 3 years I've been relapse free and I've continued to work full time more easily than before. I've even been able to redecorate my house, completely redesign my garden and do all the physical work in it.

I couldn't have done this the way I felt on Rebif, and most importantly, I've noticed no more progression!!!

I'm so glad I made the decision to try LDN.

It was a really difficult and frightening decision at the time, but it turned out to be the best thing I ever did. My MS nurse mentioned Tysabri last year but there was no way I was leaving the LDN to take a huge risk with that, when I'd been stable and happy for 3 years!

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Mike M, UK
1999 - Multiple Sclerosis
November 2004 - LDN

I started taking 4.5mg LDN back in November 2004. I'd had Mitoxantrone treatment earlier that year due to the severity and frequency of my attacks. The proposed follow-up treatment was to be 'REBIF'.

When I was in rehabilitation in Queen Square, I met a considerable number of people who were less than complimentary about 'REBIF', so I decided not to go that route, but still... nobody in the medical profession would even talk to me about LDN.

I have not had the strange dreams or any other notable side effects while on LDN, and dare I say it, but I have not had any relapses since then either. I can't say positively that LDN is helping but it's certainly not harming me.

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Nettie E, New Zealand **May 2008 - Peripheral Neuropathy, Hashimoto's Thyroiditis, Goitre** **July 2008 – LDN**

For a time I kept a detailed diary, at least, up until I started to get well, because it was the only way for me to keep track of everything while traipsing from one doctor to another.

I have at least 5 foolscap, handwritten pages from less than a one-year period, and that was just dates and symptoms and treatments. I was misdiagnosed, mis-medicated, and eventually bumped from one specialist to another, which of course made everything worse.

I began taking LDN in July 2008 for Hashimoto's, then was diagnosed with Microscopic Colitis (MC). Initially, the LDN didn't seem to help at all, but as soon as I added probiotics, digestive enzymes and a raw, natural diet to the mix I very quickly improved.

I think the enzymes and diet helped my system absorb the LDN much better and I have gone from 8 or 10 painful, watery motions a day to just one regular motion. After only 3 months on LDN my health had gone from seemingly hopeless to miraculous.

My time on LDN has been short compared to the time spent searching for answers, which I guess is pretty much the same for everyone on LDN. We all have health issues throughout our lives that we encounter and deal with.

My two-year nightmare began in August 2006 when I woke up with severe cramping in my abdomen, vomiting and diarrhoea. A trip to the ER and lots of tests revealed nothing more than dehydration.

However, a month or so later I began intermittent bleeding from the bowel. My GP thought it was just internal haemorrhoids, but recommended a routine colonoscopy just to be sure because I was nearing the magic 50 plus years. The colonoscopy was performed a few days before Christmas.

The Gastroenterologist found a large polyp and informed me, while I was still lying on the table and as he took a biopsy, that there was a 50/50 chance it was malignant.

My early Christmas present was that it wasn't malignant, yet, but I had to have it removed surgically because it was high up, on the bend between my ascending and transverse colon, and impossible to remove by colonoscopy without the risk of

perforating the bowel. By the way, a sigmoidoscopy would not have found this, so beware if you are ever in the same situation. Also, the bleeding did not recur once I had made the appointment, so I believe it was just God's way of getting my attention.

The surgery in February 2007 was straight forward, but while in hospital the nurses noted fluctuations in my B/P and suggested I see my GP once I was recovered. He wasn't concerned, but prescribed Temazepam as I was having problems getting a full night sleep (due mainly to my snoring husband). Taking Temazepam turned out to be a huge mistake on my part, but I was ignorant at the time and trusted the doctor. He wrote the Rx for numerous repeats and I blindly took it, happy to get a few more hours sleep a night.

Within a few weeks I was experiencing tremors in my hands and rapid weight loss. I finally went back to the GP and got a different medication. I asked if the sleeping pills could be causing my problems but she said, "No, no - keep taking it - you need your sleep". She diagnosed anxiety and prescribed Effexor. Only took it for two days as it made me 10 times worse.

Then she prescribed Lexapro, which I took for 3 weeks. It stopped the tremors but made my head buzz. She said that wasn't good so prescribed Paxil. The tremors didn't return, but I continued to lose weight. (25lbs over a few months, without trying - in fact - I often drank two bottles of beer after work as it was the only thing that helped slow the weight loss).

I felt progressively unwell and in September I developed electric shock symptoms and numbness in one foot. Saw yet another doctor who told me I was 'obviously anxious as he could hear it in my voice' and told me to increase the Paxil and add Naproxen for the tarsal tunnel syndrome. This was despite the fact that my B/P had climbed to 170/110, but he ignored that and my protestations that there was 'something wrong'.

Two days later I called back into the clinic to have my B/P re-checked as I felt worse than ever. The nurse told me it was 170/120, that it shouldn't have gone up that much in two days and to see a doctor straight away. I saw doctor number 4, and at last I was viewed as someone who was sick.

He immediately reduced the Paxil and added B/P meds, referred me to a Neurologist, as well as ordering other tests. My blood pressure fell dramatically within a few days, but before I got to see the Neurologist I had one episode of extreme weakness in my legs, finding myself unable to stand for more than a few seconds at a time.

The Neurologist seemed concerned: I had stocking glove paresthesia in all four extremities and he told me I had Peripheral Neuropathy of which there could be a 100 causes, but he was most concerned about Myasthenia Gravis.

He ordered up a bunch of tests and said he would see me in a month for the results. I read up about PN and MG on the internet and found that the B/P meds that I had been given should not be given to patients with MG, and since my muscles were becoming weaker every day, I returned to my GP to have the Rx changed.

On October 30th while at work, my world turned upside-down when I developed shooting pains in my jaw while eating grapes, and then the whole left side of my face went numb. I felt it tingle and go progressively numb over just a few minutes.

I actually took a paperclip (working a desk job has its benefits) and stabbed both sides of my face to be sure. Panic ensued, co-workers gathered, husband was rung and he came immediately to take me to the ER. I found that my legs were very weak and would barely support me to stand, never mind walk without support.

A CT scan revealed nothing, but the Neurologist assured me, by phone, that the MRI he had ordered for next week was bound to tell him something. It was decided I couldn't return to work in the meantime as I had to drive half an hour each way and it was simply too risky. My symptoms came and went, but I never knew how I was going to feel one minute to the next.

With nothing else to do, I hit the internet, and a few days later, to my horror, I discovered that the drugs I had been given should never be taken together - not even within 14 days of each other!! The Temazepam should only have been Rx for a 10-14 day period and then re-evaluated. I was never told all the foods that I shouldn't take with it - and it turned out they were all my favorite foods. The only thing I was aware of when I began taking Temazepam was the warning that taking it with alcohol could make me drowsy. Duh! I was taking it to help me sleep, so what was wrong with that?

I went straight to my GP and asked that I be taken off Paxil and Temazepam.

He assured me there would be no withdrawal affects from the Paxil since I was on the lowest dose (wrong, but that's another story). He put me on a decreasing dose of Temazepam over a week to wean me off. If I thought I had had trouble sleeping before, this was something else, but I was determined to get through it. The withdrawal was awful, but the damage was done - and November 2007 was the worst month of my life. Was it the drugs, did I have some yet to be diagnosed illness, was I going to get worse, or was I going to get better? All I could do was wait to see the Neurologist on the 19th.

What an anti-climax. Tests all revealed nothing, he said, and he recommended taking a wait and see approach. I was flabbergasted. He knew I was off work, he knew I had had a major collapse, yet he seemed not to care. So I laid into him with my findings about the drug reactions. He told me there was no way that the drugs could be causing my symptoms, so I left his office with an order for a Spinal Tap which was performed the following week. One of the new symptoms was electric shock sensations down both arms whenever I turned my head and I knew this could be an MS symptom, so I had to have the Spinal Tap to be sure. Results? Nada, but no surprise to me by this stage.

So where did all this leave me? I was convinced I'd been damaged by the drugs prescribed to me, but was without a doctor who would admit it, and without any help whatsoever to aid in my recovery. If I did have an underlying disease, it was either exacerbated or triggered by the drugs. But what did I have? Where would I turn? You guessed it - the internet.

To cut a very long story short (I know, too late) I basically dealt with each symptom separately, since looking at myself as a whole was too confusing. I wasted a lot of time waiting for appointments to see specialists (my GP tried to get me into Mayo, but they declined), and waiting for test results, most of which I asked my GP to run as I read more and more about my 'condition'.

I became convinced early on that I had developed a Thyroid condition, but which one? My symptoms continued to change on a daily and weekly basis, so my theories had to change too, but the Thyroid remained at the top of the list. Actually, the thyroid and

drug withdrawal pretty much covered everything, but with no confirmation of my theories, it was impossible to just quit. I was also convinced that I was suffering from some sort of autoimmune disease or diseases and read books galore on the subject.

In January 2008, I found a wonderful Chiropractor who hit the internet too, researching everything I was telling him in an effort to understand and help me. He did reduce a lot of my pain but after a few months I had reached a plateau. When I lost my job and my health insurance and had to sell my car, I had no choice but to stop going to see him.

The third Neurologist I saw finally had a hit with a test for TPA (Thyroid Peroxidase Antibodies), which measured 170 instead of the norm of less than 30. He referred me to an Endocrinologist. More waiting.

Finally was seen by her at the end of May and she diagnosed a goitre, Hashimoto's Thyroiditis and low levels of Vitamin D. I was relieved, for about 5 minutes, until she told me that my symptoms could not be due to the goitre or the HT and that I should take Vitamin D to improve my muscle strength, try T4 (though she doubted it would help), and get more exercise.

Now I am not overweight, I have always eaten well, exercised regularly, and worked hard - 40 hours a week plus spent my weekends renovating my home - really hard physical work. Now I was simply not capable of exercising - muscle pain and weakness and fatigue made it impossible to do much more than care for myself.

I looked at the side-effects of the T4 and was horrified, once again, to read that it could cause all of the symptoms I was already suffering, and more. I told her I had chronic diarrhoea, but she didn't appear concerned. In the last few months I had tested negative for Celiac and Whipples, so I think she decided I was simply lying about it. With no other options available to me I tried the T4, but it made me far worse. The diarrhoea worsened (and I didn't think that was even possible). I had the worst 3-day migraine I have ever had, and so I after a month I threw the T4 in the bin.

It was time to speak up and take charge of my own health for once and for all. I had been reading over the preceding months about LDN and how it had been doing wondrous things for all manner of people with autoimmune diseases. I had asked numerous doctors about it during my appointments, but they all scoffed at such an idea. With nothing left to lose I returned to my GP.

God bless this man because he believed in me all along and ordered up every test I asked of him. I told him I was done with specialists and tests and all I wanted was a Rx for LDN - that if he wouldn't write it for me I knew people and I would get it - it would just take me a bit longer. He simply said, 'Yes, I know you have done your research - just give me some information on LDN for your file'. If only all our doctors could be as open and caring as this man. I had my Rx for 1.5mg up to 3 times a day, the very next day.

I took my first dose of 1.5mg on July 18th and continued taking that for one week, suffered no sleep disturbances, so increased to 3mg. Almost immediately I felt an improvement in my energy, the pain and dysesthesia in my knee all but disappeared, and I felt an overwhelming sense of hope for the first time in more than a year. I tried increasing to 4.5mg after a few weeks as the diarrhoea would not settle down at all, but my leg muscles became stiffer so I dropped it back to 3mg.

Life was good, but I knew it could get even better. I had had an appointment arranged at one point, in early July, to see a Gastroenterologist, but had to postpone due to a clash with an interview with the INS. Anyone who has had dealings with this department knows you do not mess with the INS. I became a US citizen on August 6th, following that interview.

My new appointment was scheduled for late August and when I finally got there I was feeling so good, I didn't even bother telling him my whole history. I just said I wanted to be re-checked for any more pre-cancerous polyps, and while he was in there, to please take some biopsies to check for Microscopic Colitis. This was the only disease left that I could find that explained my unending diarrhoea. He felt that it was probably caused by bacterial overgrowth, due to half my bowel and the ileocecal valve being missing, but agreed to the biopsies. He did prescribe a course of antibiotics in the meantime, but to no avail.

The colonoscopy was set up for September and to everyone's surprise, not only did I have a couple more pre-cancerous polyps (small and easily removed), I also had Microscopic Colitis.

The Gastroenterologist wrote a prescription for Asacol. I had already studied the possible treatments and was far from happy with the prospect of taking yet another drug with horrible side-effects. This one even included possible hair loss, so I wasn't holding out much hope for a happy relationship with it. Four days!!! That was as long as I could tolerate it. I guess I can't complain - it stopped the diarrhoea. It stopped me up so darn well, I may as well have had a cork plugged in me. And the nausea!! Terrible!!

Took me a week to go again, and in the meantime I began a diet called 'Great Taste, No Pain' by Sherry Brescia.

Guess what? Once I got going again, no pain and no diarrhoea. It was like a miracle. Between the LDN and the diet, I was cured. I say cured because unless I stray from my diet (and it isn't a difficult diet, just avoiding certain food combinations rather than eliminating any foods), I have no issues whatsoever!

I have cut my coffee consumption to one cup a day - I used to drink at least three - and I drink green tea instead. That is the biggest change I have made. To be honest, I don't miss the coffee, and often can't finish my one cup. Love the smell, but the taste just isn't the same anymore.

By the way, I have never before been contacted by a Pharmacy regarding a prescription I had been taking, but I was contacted - not once, not twice, but three times by the Pharmacy who dispensed the Asacol!

I was encouraged to continue taking Asacol, that it was the only way I was going to get well, that I would never be able to cure the MC, just control it. Poppycock!! It just goes to show how much money the drug companies are making when they try so hard to keep patients on their drugs. And this crap was not cheap... the first month cost me \$45. (I should have taken back the 26 unused days worth of pills for a refund - lol).

This is my story ... It has changed forever the way I view the medical profession ... It has changed my whole perspective on life ... But most of all, it has given me the

confidence to question, question, question and to demand what I believe is right, without exception.

No-one knows your body like you do, and no-one has the right to tell you how you feel or what is best for you. Fight on, my friends - we are not alone. LDN should be the first line of defence, not the final, last-ditch attempt. I will never quit taking it.

UPDATE: March 2009: No real changes for me except that I am now living in New Zealand and I've found a doctor who's just 20 minutes from my home and prescribes LDN. Could not believe my luck!! I continue to take 3mg of LDN each morning.

I'm working 6 days a week full time in two very physical jobs with no adverse effects to my health. I hope to eventually get a job as a support worker for the intellectually handicapped and the physically disabled.

I hope this helps someone.

68

Nikolaos P, UK
March 2007 - Multiple Sclerosis
November 2007 - LDN

Before I was diagnosed in March 2007, I was leading a happy, stress free life. I was working as a background artiste and music composer.

After I went to hospital, the whole world collapsed around me. While in hospital, my Neurologist (who, incidentally, I saw only while in hospital), had the clever idea to give me a course of strong steroid treatment, without knowing, or telling me, what I was suffering from!

His team said that the steroid treatment would bring the inflammation down, but he failed to tell me what he thought my illness was, or ask if I wanted to have the treatment! After I was dismissed, I developed my main symptom; HEAT intolerance; which I believe was caused by the steroid treatment.

When I was told about the NHS approved drugs for MS I was horrified. My Neurologist in Queen's square advised me to start treatment immediately. When I asked her for LDN, she agreed but stressed that this was not an NHS recognised treatment.

After 1 year of taking LDN, I requested from her an MRI scan to monitor disease progression. She refused to order a scan on the grounds that MRIs are used for diagnosis purposes only, BUT, she said she was willing to authorise a scan IF I agreed to start treatment with interferon.

I argued that I was on alternative treatments and managing my MS via diet and LDN, but she still refused.

After LDN, I regained hope and optimism. I've had no side effects from LDN, and best of all, there are no painful needles. I'm happy to take LDN until I fully recover, which I believe strongly will happen.

69

Pami, USA
18th March 2008 - Breast Cancer (BRCA 1)
April 2008 - LDN

I was diagnosed with Breast Cancer (BRCA 1) on 18th March 2008. I had a bilateral on 15th April 2008. I refused chemotherapy, then started on LDN.

I take LDN most days and get it prescribed from Dr McCandless.

I am cancer free to-date.

I have always been a vegan and teach that to others. I feel that food is your most important defence.

I have no way of knowing whether it is the LDN or my lifestyle that is working, but I feel something is.

70

Pat P, USA

June 1993 – Multiple Sclerosis

October 2006 – LDN

I am a woman in my mid 60s with MS. I had my first exacerbation at 15. I began taking LDN shortly after a disastrous attempt to take Rebif. It (the Rebif) resulted in one of the worst exacerbations I have ever had.

Although my life has been stressful, since I've been taking LDN, I have not had an exacerbation.

I am not symptom free, and I do feel there is some slow progression... but I no longer have those horrible exacerbations. For that I am very grateful.

I am on a low fixed income so I am grateful I can obtain LDN at a very low cost.

I have an MRI scheduled for early September, so I'm going to be very curious to see what it looks like.

71

Patrick R, UK

August 2000 - Secondary Progressive Multiple Sclerosis (SPMS)

mid 2008 - LDN

The first symptoms developed in 1999, but I wasn't diagnosed until August 2000. I started taking LDN about 5 years ago at 3mg but I stopped taking it after a while due to badly disturbed sleep that affected my fatigue levels.

However, I was working for a stressful boss in a stressful industry full time.

I restarted taking LDN about a year ago because I was continually having to wear a prosthesis bag as my bladder was out of control and I remembered that the LDN helped first time around with this problem.

I can now go to work and wear just a pad and only wear my prosthesis bag when I am going out the house either for a long time or I am unsure where the toilets are. So the LDN has improved my bladder control.

Also, in the last month I've noticed my pins & needles in the base of my spine and legs has gone!

I am now taking 4.5mg and my sleep is less disturbed. I am working less hours for a less stressful company, so whether that has anything to do with my improved sleep, I do not know. I still wake up about 4.5 hours after taking LDN but I can get back to sleep a lot easier.

I have secondary progressive MS & can walk a small distance, however, LDN does not seem to have helped with the slowing down of the progression of the illness or my mobility problems but it has helped with my quality of life with regard my bladder issues.

72

Pat U, USA

Feb 1995 – Multiple Sclerosis

Sep 2003 – Crohn's Disease

3 March 2009 - LDN

In mid-February, 1995, over the course of 4 or 5 days, my body progressively went numb from my feet to my chest. My feet felt like they were in ice buckets and I couldn't tell when my socks bunched in my shoes.

I went to the emergency room, thinking this was related to back surgery I had several years prior. Unable to find anything, they sent me home. When the numbness continued to progress, I returned to the emergency room and was admitted. A spinal tap confirmed my MS diagnosis. I was given Solumedrol infusions and sent home with instructions to see a neurologist. Avonex and Amantadine were prescribed. From 1995 until 2009, I had only two small exacerbations. The tops of my feet are still numb, but thankfully that is my only neurological deficit.

In the fall of 2003, I began to experience bloody stools. After a colonoscopy, I was given the diagnosis of Crohn's Disease. I was hospitalised three times in 9 months, becoming malnourished and anemic with each bout. 6MP was prescribed but I was found to be part of the population that is unable to tolerate it. Prednisone was then prescribed, which had marginal benefits compared to the side effects. I had two infusions of Remicade but it potentiated my MS symptoms.

The next attempt was Budesonide, which was better tolerated than Prednisone and helped calm flares. I was put on a maintenance dose of Methotrexate. A week after being dismissed from the hospital the third time in 2003 for Crohn's, I fell off a horse while on vacation in a semi remote area of the mountains. I was airlifted by helicopter to a nearby city and in the hospital for three weeks recovering from a head injury. 2003 was a year from hell!

In the spring of 2005, I read an article in a wellness magazine about LDN and its success with MS. I had reached a level of stability with my Crohn's and head injury and wasn't ready to 'rock the boat' medicinally, but mentally filed the information away. In 2006, my sister was diagnosed with PPMS and my other sister was having suspicious events, causing her to wonder as well.

In November 2008, my daughter, in her late 20s, was diagnosed with MS. I then spent days on the internet reading everything I could about LDN. She did not want to take any of the CRAB drugs after reading about their side effects, and wanted to try LDN. Her neurologist was not in favor of her taking LDN. She sent her records to a physician out of state and had a phone consult. He prescribed LDN and the prescription arrived from Skip's in just a few days. I also sent my records to the doctor, had a phone consult and received an Rx for LDN. I stopped taking Amantadine, Avonex, and Methotrexate and began taking LDN on March 3, 2009.

After my MS diagnosis, I altered my diet to a low saturated fat diet, following Dr Swank's advice in his MS Diet Book. I have no way of telling whether or not it has helped over the years, but it is regarded as a healthy diet for anyone and I wanted to give my body every chance at keeping the dreaded MS beast at bay.

After my Crohn's diagnosis, I didn't significantly alter my diet, other than reducing most dairy products except for yoghurt.

I also introduced supplements to my regimen, and I take the following daily: Iron 20mg, cholest 600mg twice daily, calcium/magnesium 500mg twice daily, vitamin D3 1000iu daily, vitamin B6 200mg daily, DHEA 20mg daily.

When I began taking LDN capsules with avicel filler, I started on a 1.5mg dose for three weeks, stepped up to 3.0mg for two weeks and then 4.5mg. I take it in the evening between 10.00 and 12.00pm. Prior to starting LDN, I had been on a downhill slide with Crohn's for a couple of months. Two weeks after stopping Methotrexate, I had a flare.

After talking to Dr Skip of Skip's Pharmacy about whether or not I could take LDN and Budesonide (which I knew my gastro would prescribe) at the same time, he said that Dr Jill Smith did not require her patients be off steroids while taking LDN during her Penn State trials.

I went armed with LDN info to my appointment with my gastro. At least he was willing to listen and read the info and not usher me out the door! So I took Budesonide along with LDN for a time, and the two seemed to work together to keep me out of the hospital.

I titrated the Budesonide dose down to 3mg in early May, but again found myself dealing with bloody stools. Following my gastroenterologist's instructions, I went back up to 6mg for four weeks and am currently alternating between 3mg and 6mg, with the

intent of tapering down to 3mg daily during the next week and then hopefully, zero, a few weeks after that!

During my telephone consult with my LDN physician on July 27, 2009, he prescribed not only a refill for the 4.5mg evening dose of LDN, but suggested I also take 1.5mg in the morning. Every body responds differently, he said.

It is now 27 July 2009. I've been off immunosuppressant drugs since 3 March 2009, and my only prescription meds are LDN and the temporary Budesonide! Hurray!

I try to go to the gym 3-4 times a week for cardio and strength workouts. In addition, my dog encourages me to go for a walk every day.

A delightful, and unexpected result of being off immunosuppressant drugs is that I have 'me' back. I now enjoy playing the piano, I have 'happy' thoughts, and I have rediscovered my creative side. I'm happy even though there are still struggles in life. I care about living again. It's been a long 14 years without feeling joy.

73

Paul B, PA-C, Physician Assistant, USA

2004 - Crohn's Disease

January 2008 - LDN

My son developed the first symptoms of Crohn's in 2003 at 9 years of age, and it proved to be severe, resulting in a 60 cm small bowel resection at the young age of 10.

After being on Imuran for almost 4 years, he had a flare from his gastric mucosa to his descending colon, and developed hypovolemic shock. None of the drugs he was prescribed helped him, nor did the surgery. When he got out of the hospital he was still not normal.

When I learned of low dose naltrexone as a treatment option, I researched it further and decided it was worth trying.

I started him on low dose naltrexone (LDN) in January 2008, and within 2 weeks his color had returned and his energy was back to normal. At his follow up examination 5 months later, his lab results were the best they'd been since diagnosis.

He's had NO flare ups since. He still has symptoms of cramping, but only when he does not follow his diet, and it's been 18 months now.

This is how our story started:

In October 2003, I took my ten year old son to the Pediatrician to investigate severe fatigue, and why he'd gained no weight in two years.

I have been a Physician Assistant (PA) for 27 years, so I strongly encouraged the Pediatrician to run some basic blood tests. Due to the blood tests revealing extremely low levels of iron, the Pediatrician recommended iron supplements.

We tried 6 different iron preparations, and my son vomited with each one, so we again consulted the Pediatrician. I suggested finding out why he was anemic, and to perform tests to rule out Celiac disease. The doctor agreed, and his TGG test was slightly high, suggestive of possible celiac.

In November 2003 we saw a Pediatric Gastroenterologist. He scheduled my son for upper and lower endoscopies performed over the following two months, resulting in a diagnosis of Crohn's disease in January 2004, and a prescription for Prednisone at the same appointment.

The same month we had to consult a surgeon due to my son developing an abdominal distention, and incapacity to eat. The surgeon recommended surgery to address my son's obstruction.

During surgery in February 2004, 60 cm of his small bowel was involved with the disease as opposed to the predicted 10 cm on the CT scan. Therefore that segment was resected. The pathology report showed it was nearly perforated.

He was prescribed Prednisone for 6 weeks, and Imuran permanently. My son began to recover and gain weight. Blood tests revealed his Hgb went up to 11.8.

In May 2004 we started supplementing his diet with 300mg of fish oil per day.

Between May 2004 and November 2007, he did well on 150mg Imuran per day, but on 29th October 2007 he developed tremendous diarrhoea and lost 19 pounds, with his weight slipping from 116lbs to 97lbs in 5 days.

Hypovolemic shock followed, and we nearly lost our son.

Repeat CT scans were taken, and upper and lower endoscopies performed. They revealed active Crohn's from my son's stomach to his lower bowel, with abscesses in his stomach and throughout his whole intestinal tract, as well as granulomas.

He was treated with antibiotics, Azacol, and Flagyl, fed IV nutrition. He was still not doing well but was discharged. The Children's Hospital staff couldn't find a cause. Cultures for bacteria, viruses, and fungus were negative. His CRP was 20. He was discharged to go home. All medications, with the exception of Imuran, were discontinued. He seemed to stabilize but was still not doing great.

We increased his Fish oil from 300mg daily to 600mg per day after he was discharged.

In December 2007, his Hgb was still only 12.2. It had hovered around that level since he was 10, and since he'd begun taking Imuran medication nearly 4 years earlier.

In January 2008 we heard of a treatment called low dose naltrexone (LDN), and we consulted with Dr Grossman about the possibility of our son taking LDN.

In January 2008, our son started on 1.5mg naltrexone for 3 weeks, then 3.0mg for 3 weeks, then took 4.5mg every night thereafter.

Within 2 weeks of starting the 1.5mg and tapering down the Imuran, our son's color looked better, he became more active, and was off the Imuran completely by the time he was taking 4.5mg naltrexone.

In May 2008, he was active enough to return to BMX biking, but also due to that activity, ruptured his spleen.

The blood test taken for his Gastroenterologist follow-up was promising. His Hgb was up to 15.5, higher than it had ever been since he grew sick – and his CRP (inflammatory marker) was less than 0.5. When he'd been hospitalised, his CRP had been 20.

His glutamine and magnesium were low on a spectra-cell blood test, and his B12 was slightly low also. We started him on 5 grams of Glutamine, 300mg of magnesium, and a multivitamin with Iron each day. We also started him on probiotics.

By June 2009 he hadn't had any flare ups since commencing LDN in January 2008, 17 months earlier. He was 15 years old, and had grown to 5'9" and 142 pounds. He looked healthy and was continuing to have normal bowel movements.

He still gets cramps if he doesn't maintain his dietary restrictions.

He does not eat sugar or milk products, and his bread intake is limited.

In June 2009, his CRP was 1.1 (less than .8 is considered normal), so it is up a little. Hgb was 14.1 (normal range 13.4-18.0). His ferritin was 26 (normal range 20-380), and his Iron was 37 (normal range 40-225).

I had started but stopped giving him a daily multivitamin with 18mg Iron per day due to him experiencing nausea in 2008, so I am now going to start him on a multivitamin with a lower iron component at 9mg. I'm also putting him on B12, and a combined B6/Folate supplement.

I also have him on Vit D3 50,000iu once every 2 weeks because his Vitamin D test result was 29. Our goal is to get it into the 60-70 range.

We are increasing his D3 to 50,000iu every 10 days, and his fish oil to 900mg per day.

The fish oil was originally started for a different reason back in 2004, because he had symptoms of ADD. A Purdue University study had shown kids with mental disorders often had low Omega 3 Fatty Acids (FA), so I started him on it for that reason.

We're continuing the probiotics, and have added Sacchomyces, which might help minimize yeast, and has reduced his flatus substantially. The probiotics are from Prothera/Klaire as suggested by my Dr Jaquelyn McCandless who has treated many autistic children with LDN and probiotics.

The time he takes his naltrexone varies with his teenage lifestyle, but in general he takes it at about 10 pm each night. I asked Belmar pharmacy what filler they use in his

capsules, but the pharmacy will not tell me. They said it is proprietary. I think I will have to challenge them on that.

I also have a friend with MS who started on LDN, and 4 months later had more energy than they'd had in the previous 5 years - and they were able to go off Rebif.

74

Paul W, UK
2005 - Kidney Cancer
July 2007 - LDN

I lost a kidney to cancer back in late 2005.

A year after surgery, in late 2006, I was told my cancer had returned and my prognosis for survival was from 2 to 2 ½ years.

I heard about LDN in July 2007 and I've been taking it ever since. My two and a half years has just ended, and I defy anyone to find a fitter 55 year old (well, almost anyone)!

75

Paul C, UK
2004 - Multiple Sclerosis
3 October 2008 - LDN

My name is Paul and I've been taking LDN since October 2008.

I have had MS since 1996 (diagnosed in 2004) and was on Avonex for about 4 years but couldn't bear the flu symptoms, although I did persevere with it until I came across LDN quite by accident.

I stopped using Avonex, and took my first LDN capsule on 3rd October. I noticed an immediate improvement the following day, which was a Saturday and shopping was on the cards - something I never looked forward to because I live on my own and am forced to do everything for myself or not at all.

Other, noticeable, improvements were lack of fatigue, vastly improved bladder control and a 'can do' feeling even though I know I can't - like the days before I got sick when I was firing on all four cylinders, only now it's 24/7. Oh, and there's no depression now either. LDN has given me my life back.

76

Paul S, Australia
2004 - Primary Progressive Multiple Sclerosis (PPMS)
February 2009 - LDN

I have been using LDN for Multiple Sclerosis now for over 7 months.

I have found it is helping me with fatigue, as well as my speech. This is not in my mind, as I have been told this by other MS people who have been keeping a close eye on me since I started using this drug, and so have doctors.

At this stage I'm very, very, very impressed with LDN, and I thank you so much for giving me another chance in dealing with these MS problems.

I have Primary Progressive Multiple Sclerosis. I was diagnosed in December 2004 - a great Christmas present !!

I was told I would only go downhill, and there were no drugs out there to help with this medical problem.

I was very determined to try LDN, but, no-one here would prescribe it, so I showed your information to a heroin doctor as was told that I was the first MS person to ever come to him about this drug, and that he would only give it to me if I wrote a daily diary, which I did, and so far he is also impressed.

77

Peter S, UK
May 1996 – Relapsing Remitting Multiple Sclerosis
2009 – Primary Progressive Multiple Sclerosis
April 2009 – LDN

I was diagnosed with Relapsing Remitting Multiple Sclerosis in May 1996, and I was started on Beta Feron in Nov 1996.

I injected myself for 3 years with Beta Feron before my Consultant said my MS had progressed to Secondary Progressive, and took me off the Beta Feron. This change coincided with the NICE report on the effectiveness of the drug (and of course the costs)!

The only drug then available to me was a particularly aggressive drug, which can cause hardening of the heart and can only be taken for three years, so no good news there!

A pal of my fathers sent a national newspaper cutting about LDN to him so he could pass it on to me.

I immediately made contact with Dr Bob Lawrence and received sheets of information about LDN, recommended supplements, and advice.

My condition prior to starting on LDN was good, and the fact is... a drug that has possibility of improving my lot is of great psychological benefit.

I started taking liquid LDN at 3ml, and it was only when this was increased to 4ml that I went through a short period of discomfort. I'm due to start on the compounded capsule form very shortly.

I hope a trial of LDN for MS is started, so that others can see the worthiness of the drug and so it can be made available to sufferers of MS who, like myself, will grasp at any chance to improve their lives.

I hope one day a drug to halt MS will be found, but in the meantime, give this a shot. I have only been taking LDN since April, but have already got a feeling of well-being, and friends and family have told me that I look 'good'. The cost of this treatment is not outrageous, and for me that's a huge plus.

PN – ANON, UK
2006 - Primary Progressive Multiple Sclerosis
September 2008 - LDN

My Other Half has PPMS. It was diagnosed in 2006 after a year or so of tests that included a Lumbar Puncture, several MRI scans, and evoked response tests.

She was initially prescribed Baclofen, Gabepentin and finally Azathioprine. The high dose of Baclofen 9 x 10 mg per day, achieved over a slow build up to that amount, resulted in unpleasant side effects. Fatigue was bad, but worse was the decline in her ability to concentrate. Gabepentin helped with her ocular neuritis.

After 9 months on Azathioprine, there was still no indication that progression had been reduced or become stable. Worse still was the effect azathioprine was having. Several months into this drug therapy her appetite was affected. She constantly complained of stomach pains and after 6 months experienced several asthma attacks (not something she had experienced since 2002).

After reading MS websites we became aware of LDN, and although our first thoughts on this were cynical we decided to give it a go. However, my partner's Neuro consultant would not prescribe and neither would her GP. We finally sourced LDN privately.

My partner had to come off Azathioprine before she could start on LDN. This she did over a period of about 1 month. We opted for liquid LDN because it would be easier to control the initial start-up dose, and gradually increase. Neither of us believed it would be beneficial.

Several weeks after reaching the 4mg dose, she started to experience improvement in balance and no longer needed my assistance to get her from kitchen to lounge. The spongy feeling in her feet started to improve, numbness in her hands slightly improved, and ocular neuritis disappeared completely. The incontinence problems have not improved though. From my own observations her mental alertness also improved, but I felt... could be all coincidence, could be all in the mind.

At the end of July this year my partner got a severe chest infection. Given her history of asthma, her GP prescribed a large dose of prednisolone, and that meant she had to come off LDN for 10 days.

The prednisolone worked and her chest and breathing ability returned to normal. She had no problems for about a week after stopping LDN, then ocular neuritis returned. After about 10 days, her feet started to feel fuzzy again and her balance was not as good. Again, could be all a coincidence, could be all in the mind.

She has now been back on LDN for about three weeks. Her ocular neuritis is gone, her balance is better, and she is generally feeling better.

We are now less cynical about LDN. After almost a year on this medication we know it has benefits, where the other prescribed alternatives she tried were disappointing. LDN is the only medication she is now taking for her PPMS.

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Rachel R, USA

Jun 2004 – Ulcerative Colitis

Mar 2008 - Indeterminate Crohn's Disease/Ulcerative Colitis

July 2008 – LDN

In mid 2003 I noticed a bit of liquid stools in the morning, I attributed it to drinking too much alcohol the night before. I ignored it and carried Imodium for when it was needed. I had no idea that this was not normal.

I also developed unexplained hives. My PC, dermatologist and allergy docs all prescribed 40mg of evil prednisone. They DID NOT consult each other.

I developed a cyst (from an ingrown hair) and saw a new nurse practitioner who lanced the cyst and put me on Doxycycline. I had never taken this type of medication before and didn't know what to expect. I started eating Activia and taking probiotics, but the diarrhoea came on and didn't stop after I stopped the antibiotics.

Then the blood showed up in my stools and I lost 35lbs in 5 weeks. By now it was time for my youngest child to graduate from High school and my parents were here to visit and attend the graduation (read: STRESS).

I saw my first Gastroenterologist (GI) in June 2004 and was told that I had Ulcerative Colitis. I was put on Asacol and 60mg of prednisone. I had now been on 40 to 60mg of prednisone for about 10 months.

The prednisone attacked my pancreas and I developed Type 2 diabetes. My hair fell out (I'm a hair dresser, licensed for 30 years) and I knew that it was because of the evil prednisone and the disease.

The GI put me on 6mp, but that eventually shut down my liver and landed me in the hospital for 6 days. And, of course, I picked up C-Diff. I tried Remicade and it kicked in within 48 hours, but I eventually became allergic to it. I tried Humira in various doses and it did not work. I am afraid to try any other biologics.

My uncle (dad's youngest brother) had Ulcerative Colitis, leukemia and other issues, and passed from complications. His son (my cousin) was recently diagnosed with ALS and UC. He was very near death while on Humira. He had his colon removed and is now slowly regaining some strength. His girlfriend got him LDN from Skip's, but I don't think he has started it yet.

I have now been on LDN for almost a year. I am not in remission, but I am able to work part-time. My son was married late in 2008 and my daughter got married in June of this year. I KNOW that if it weren't for LDN I would have ended up in the hospital. I did go into a flare after my daughter's wedding, but I only bled one day, and I haven't had an 'accident' in months!

I am having a lot of pain and bloating in my upper abdomen, so my new GI is sending me to the University of Florida in Gainesville for a 3rd opinion from the top specialist in Irritable Bowel Diseases (IBD). Since I won't take the evil prednisone or biologics, everyone says I am a 'complicated case'. I still think that the only reason that I'm not in the hospital is LDN.

I'm presently taking Balsalazide Disodium (Colazal) 3 750mg capsules 3 x per day. I've taken the evil prednisone, Asacol, 6mp, Remicade and Humira – one after the other, all before I started LDN. (I didn't take them all at once.)

The prednisone attacked my pancreas and I am now diabetic. The 6mp shut down my liver and gave me drug-induced hepatitis. After 6 days in the hospital and getting rid of the nasty drugs (May '05) I am only taking Colazal and LDN and Imodium and Lomotil (as needed) for my CD/UC. I use Gas-X and Pepcid complete and Nulev, too.

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Raynor H, UK

2000 - Relapsing Remitting Multiple Sclerosis (RRMS)

10 July 2009 - LDN

I've had Multiple Sclerosis for 9 years now.

I recently started taking low dose naltrexone (LDN) and am amazed with the improvement I've had for my Relapsing Remitting MS. I'd been suffering with walking problems, and was deeply fatigued. I had to sleep for 2 hours every afternoon.

I now just rest for 20 minutes, and my walking is amazing. I'm really glad I came across LDN because it's changed my life for the better.

More should be done to make LDN available to everyone. It could change someone's life.

81

Rebecca S, UK
1994 - Slow Progressive Multiple Sclerosis
Jan 2008 - LDN

I have slow progressive MS. I was diagnosed in 1994 and am in my early fifties.

I have been on LDN now for about a year. Six months ago, I managed to persuade my Doctor (with the help of the local MS nurse) to get it on NHS prescription.

Ironically it costs the NHS £120 per month to source it when I was getting it for £30 a month from Dickson's Chemist in Glasgow!

I do feel much better. Before I went on it I was starting to go through a bad time, I felt like I was recovering from flu, I had no energy and was sinking into real depression. I noticed almost immediate effects, I don't know if some of it was psychological from being able to find something that might help, but I did feel better and best of all the depression got much better.

Recently I have forgotten to take my LDN for some time and have noticed that I am getting very tearful and upset about things, so am now making sure I take it on a regular basis again.

Yes, I do think it has made a positive difference to my life.

82

Sal A, Australia
1980s – Multiple Sclerosis
5 December 2007 - LDN

I've had MS for over 20 years now, and for most of that, my GP would treat symptoms as they arose.

This was because I'd refused to have a Lumbar Puncture (LP) due to past problems with an epidural. As a result, my neuro said he couldn't provide a definitive diagnosis or prescribe the CRAB drugs (which I told him I wouldn't take anyway). I couldn't have an LP or epidural because I was told NOT TO, unless I was in a life-threatening situation, because of past problems.

My regular neurologist, and 2 other neurologists, all said I needed to have a LP to officially confirm an MS diagnosis - even though they all said they were 100% sure I had MS. Then one finally diagnosed me with MS around 2004.

I'd done a lot of research because I guess I have always been a rebel and don't take what the first doctor tells me as being true.

All I can say is that when you do your own research you will find that even the 'experts' can't agree on causes and treatments of MS. The 'experts' all stick to their little book with the MS protocol. Fact is there is no real treatment for progressive MS. None of the CRAB drugs (Avonex, Rebif etc) are for progressive MS. They state that the earlier these drugs are started for MS the better. Once you have progressed they don't work.

I did a lot of research for many years and simply figured that the odds of MAYBE being one of the 30% and getting a 33% improvement was not good enough considering the nasty side effects of those drugs. Then Tysabri came on the market, was withdrawn from the market, then went back on the market. That told me that this drug was also not good enough.

You will find many theories on MS - chicken pox caused it, a virus, a higher prevalence in cold climates. Many areas around the world like northern Europe, Scotland, the southern states in Australia, etc have cold climates and have the highest rates of MS – but now many other people in hotter climates also get MS.

One Italian research team (there have been others too) came up with the theory that MS is a metabolic issue, lack of nutrients such as zinc, copper, vitamin B's, etc. My personal thoughts are that the chemicals in our food have a lot to do with it - maybe these chemicals stop our body from ingesting the normal vitamins and minerals we need.

When you have MS the 'experts' tell you your immune system is over-active and needs to be suppressed, but LDN does not suppress our immune systems, it boosts it.

I found out about a treatment called low dose naltrexone (LDN) when I was researching on the net about 3 or 4 years ago, but I had problems getting a doctor to allow me to try it. Around the middle of 2007 I came across it again. I knew it wasn't a mainstream approved treatment, but it sounded promising and I wanted to try it.

I had stopped seeing neurologists, etc because it was a waste of time and lots of money. I'd refused the CRAB drugs they offered and instead, tried to find my own way through improved nutrition and supplementation, and I'd been seeing a brilliant chiropractor and acupuncturist whose treatments had helped some.

My cardio doc had recommended taking CoQ10, and a good quality fish oil for high cholesterol problems (because I couldn't take drugs like Zocor that make my muscle problems much worse), and I'd also done some research on magnesium and other supplements.

When I asked my GP what brands to buy (good ones), his reply was 'I'm a medical doctor and don't have the time to look at alternative medicine', so when I decided to approach him about LDN, I went prepared.

I'd found the 'How to ask your doctor for LDN' guidelines, but after printing all the info and approaching both my GP and Neurologist, neither would prescribe it for me. They wouldn't even think about it.

I was even prepared to sign a waiver but it was still a no go with my GP. His answer was that if LDN was any good for anything Australia would know about it, bah humbug!!! My GP refused to read the info I took because he had no time. Most of the medical centres near me would not take on new patients, which was another problem. So I dug my heels in and refused to go back to the neuro, and cancelled my future appointment with him.

I needed to find a good doctor. My adult daughter also suffered, from Fibromyalgia.

Well, I finally found a doctor to prescribe the LDN and I started in December 2007, thanks to Crystal of the Yahoo lowdosenaltrexone group.

I started on 1.5mg, and did have some minor sleep disturbances, which happened again when I increased the dose to 3mg. On 3mg I also had increased spasticity and muscle spasms, but I rode it out and they eventually abated, and I stayed on 3mg for 15 months (Dec 2007 to March 2009).

My first improvement on 1.5mg was less fatigue, but nothing else. Once I went to 3mg other things started to improve VERY slowly.

The first real improvement I noted was improved bladder control, but around the same time I developed some digestive issues. It felt like food was sitting in my stomach forever. I also had chest pain, bloating, burping, etc. I posted about this to the Yahoo LDN group and some suggested a change of filler, but I didn't think that would help.

I had an endoscopy, which showed I had gastric reflux. I went onto Zoton for a few months then stopped.

It took around six months, and by June 2008 I was doing really well.

I'm a wildlife carer, and even though we'd recently moved house around that time, I don't think I'd have coped as well if I hadn't been on LDN.

It was a nightmare move, and the house we were moving to wasn't finished and so had workmen there for over a week after we moved in – and it rained heavily during the move. Moving 6 people and 20 birds and 4 possums under those conditions was not easy! The wildlife had a tough time, and I single-handedly cleaned the house we were leaving. It took me a week but I did it.

Meanwhile, my daughter, who had just moved back from the USA, had tried LDN without success and had been prescribed weekly B12 shots by her new doc here, for her Fibromyalgia. (They'd checked her B12 before she left the USA and said it was fine.) The new doc also wanted to run a test on her for heavy metal poisoning.

My daughter's health improved a little after she was off all the awful meds the USA doctors had her on. She was on heaps of meds including methadone for Fibromyalgia. I really don't think she had that at all. I think her problems were from a total hysterectomy she had, ovaries included. She is a manager now in a retail store.

Unfortunately, nothing has really worked for her and I firmly believe she did not take LDN long enough. She only had 1 bottle of 1.5mg to begin with, and I sometimes wonder if it's not MS - following in my footsteps. I also believe the powerful drugs they

had her on worked against her. She was on around 6 or 7 heavy prescription drugs. Since going off all the drugs she has improved but still has a lot of muscle inflammation. B12 seemed to make no difference to her.

I have high cholesterol and used to take statins up until 2000, but after my first major MS flare, my body would no longer tolerate them, so I couldn't take statins anymore. I haven't had a cholesterol test since I started LDN, but I think I'll get a test done eventually because I'm interested to see what the levels are now that I am on LDN and not eating the tiniest bit of chocolate. Just don't have the time to do it right now.

In November 2008 I had been on LDN for 11 months when I had to go without it for 2 weeks due to financial difficulties. I didn't expect it to make such a huge difference, but it did. I noticed a change within 2 or 3 days, though not as bad as pre LDN. I was greatly fatigued, and my bladder issues increased, etc. Slowly after going back on LDN those symptoms went away again. So if you go off LDN and then your symptoms worsen I would say it shows LDN was working.

I had to give up full-time work a few years ago due to my MS, but now I'm doing fine and I'm much better than when I started LDN 18 months ago. I'm positive it's the LDN that's working.

Now I'm doing wildlife rescue and care. I actually started an official wildlife rescue group. We formed the group early this year and recently had our incorporation come through. The official launch of our group was earlier this year and we had a federal politician help us launch, as well as a state member and local councillors, etc. We've also had heaps of support from local and international clubs.

A lot of hard work went into getting that up and running. We had an official launch of the group jointly with a fundraiser. It was a HUGE day with politicians and VIP'S. My day started at 6am, feeding 'babies' in my care, loading the car with gear needed for the day, going to the hall and setting up at 9am so the function could start by 11am. ALL day I was on my feet because it was my job to make sure each area was functioning ok. I had to greet VIP's, do speeches etc, etc. The function wound up at 5pm and then came the cleanup. By 6pm we were cleaned up and packed up. I then went home and unpacked some stuff but left the rest for the next day.

My hubby then took me out for dinner because I was totally stuffed, major sore feet. I had also not eaten much through the day, no chance to. Was home again by 9pm and fell into bed. The next day I took it VERY easy but was soon fine again. I could NOT have done all that before LDN.

Of course I'm not cured but I am performing way better. I have way more energy, some of the symptoms have vanished, and I've had no progression. Of course I still have to be careful, make sure I get enough sleep etc. When I do have a very hectic day I have to take it easy the following day. Before starting LDN nearly every day was a bad day.

When I started LDN I was lucky that besides the LDN stopping progression I did get some symptom improvement. It wasn't an overnight improvement, more gradual. All of a sudden you think, 'Gee, I haven't had this or that, or that seems a lot better'.

Since starting LDN last December 2007, I've followed Dr Bihari's guidelines, taking 3mg LDN because of muscle spasms and spasticity, but I always intended getting to 4.5mg eventually.

Also the effects of different strengths of medications can vary in people. One person can take an antibiotic at 500mg and they're fine. I take the same and feel like throwing up. My doctor advises me to cut the pill in half and I go to 250mg, and then I'm fine.

Some with MS can't take 4.5mg straight away because it can increase muscle spasms and spasticity and that's what happened to me. I had to take 3mg for 2 or 3 days then one 4.5mg then back to 3mg. That went on for about two weeks because adjusting to 4.5mg initially gave me muscle spasms. I'm now fine on 4.5mg, no spasticity and muscle spasms have eased greatly.

For me and my MS, 3mg seemed to be the best initial dose BUT after settling in comfortably with that dose, I finally increased to 4.5mg at 15 months, and I'm fine now - though I did have to keep varying between 3mg and 4.5mg for a couple of weeks before the muscle spasms settled for me. I was determined to get to 4.5mg because it is the optimum dose, if you can tolerate it. Some people have taken 3 or 4 attempts to get to 4.5mg.

Some people get a worsening of symptoms for a while when they start LDN, then things get better. Makes sense to me that worsening symptoms do not occur if nothing is happening, so it must be doing something. For me, that just means the LDN is working!!!!!!

I also take a high-grade fish oil, occasional probiotic, and sometimes other vitamins. I follow a low fat diet and eat very little meat, simply because I'm not keen on meat and prefer fish.

I would never tell people they have to do what I do – it's an individual choice, but it's right for me and seems to be working for me. I have not had any steroids for many years now, have much less fatigue, far more energy, and can do much more now than this time last year. I do find I need a good nights sleep and can't have 2 late nights in a row, but that's a small price to pay. I do believe that stress is a big factor with MS.

Thankfully, my local GP has now come on board (after I encouraged him to go to the websites while I was sitting there in his surgery). I showed him the LDN web site where it states therapeutic value is between 1.75mg and 4.5mg, the best dose being 4.5mg. He looked at the web sites, and after I told him I had been on 3mg for over a year, he said it couldn't hurt. He commented that as long as I didn't need more and more it was okay. He has now given me a script for 12 months, and I no longer need to travel over a 100 kilometres to see the other doc.

I had one problem last year (2008) where I had a very irregular heartbeat, and ended up being taken to hospital twice by ambulance. The cardio docs wanted me to go back to a neuro. I told them to forget it, that I had fired the lot of them.

I stuck to my guns and refused a lot of what they wanted to do. They could not figure out what had caused the irregular beats. After I got out of hospital I went to see my wonderful local GP, who at first thought maybe it was the LDN, but I told him, "No way" it was the LDN.

During the conversation he mentioned chocolate being one of the things that could cause weird heartbeats, with dark chocolate being the worst. My response was, "Oh hell!" because I'd recently changed to the dark chocolate (because it was being

promoted as healthy). Seems that my body does not like the theobromine in chocolate. Needless to say, I've since stayed away from ALL chocolate. I still get ectopics but have always had them.

I only use De-Gas (Simethicone) now for my gastric reflux but I believe the LDN has helped more. When I had to go without my LDN last December I noticed the reflux came back. After going back on the LDN, within 6 weeks the gastric reflux had gone back to minor problems occasionally. Also, thinking of the Mennier's, the LDN has reduced the attacks. I did have a major attack March 2009 where I had to get a Maxolon shot but have had less minor attacks than in the last 4 years prior to LDN.

You have nothing to lose by trying LDN but give it a fair chance because some people have taken almost a year before they see the real benefits. Do I still get fatigue? Only when I have an extremely hectic long day then the next day I have to take it easy.

Just remember that the facts are there that it's working. Yes, some people get a placebo affect from meds. Give them sugar pills in a clinical trial and they swear the pills are working – for a while – but not this long.

LDN is not a magic drug that is going to cure your MS, but it works. One day maybe there will be a cure BUT in the meantime, you will see improvements with LDN if you're patient.

My bladder and bowel issues have improved greatly and I have much less fatigue and far more energy – and I have not had any blurred vision for a year.

My family are amazed at just how much I can do now.

Samreena K, UK
2005 - Multiple Sclerosis
September 2008 - LDM

I am a teacher who chose to start working part-time after my second child in 2001.

I bought an automatic car in 2003, and then in 2005 I was diagnosed with MS. Did someone prepare me for this in a discrete way?

It was my own fault really! I decided that I was going to become fitter and healthier but when everyone else was walking ahead of me and my leg started 'dragging' my brother, a doctor, reminded me that this had happened before although I couldn't remember!

So this is where the appointments began and the hospital visits started.

My doctor referred me to a neurologist who then suggested an MRI be done. As I was busy looking after the children and working I was almost on 'auto-pilot' - going through the motions and doing what the 'professionals' (doctors) wanted me to do. When the diagnosis came, I was relieved. At least I knew what it was and could 'plan, read and understand' what this was all about. As it happens, nothing could have prepared me for this other than my belief that one day I would find a way or perhaps there would even be a cure!

Jumping ahead to 2008 and two relapses later, it was suggested that I 'fit' the criteria for injections. Would I like to go along to a discussion group where I could choose my injections? Once again I went along to a discussion group, but this particular occasion was to be the 'turning point' for my MS.

Within this 'group' there was a person who said, "I'm not here for the injections but the tablets." My brother had accompanied me, so I looked at my brother thinking, 'Did you not know about these tablets?', quickly followed by, 'if you did, you've got a lot of explaining to do!'

I am grateful to my younger brother who, when I came home the following day from work told me about LDN. He had done all the research etc, and I just needed to convince my GP to write the prescription (easier said than done) - but undeterred I found a doctor who was prepared to write a prescription for LDN after having spoken to me, etc.

I informed my 'medical team' of what I was thinking... that I was going to try LDN. No one discouraged me. If it didn't work then there was always the other option of injections. No-one was going to lose anything, except me, and this was my decision; albeit one I was making alone. But then I spoke to Linda from the LDN Research Trust website. She allayed the fears I had and the first prescription was sent off.

I have been taking LDN for almost one year now. I've had no relapses and I've had less time off work. I feel better, and on most days I have more energy than before LDN. I have visited my GP less, and could go on and on about how LDN has worked for me.

I know that this is a medicine that does work and we need to let 'everyone' know about it so that an individual can make up their own mind if it is for them. I realise it is not a 'miracle' cure, but if it works then why not use it. What I have learnt is that this is my illness, and I am responsible for its treatment. I just hope the man that led me towards this journey of LDN has found it as well.

At the moment I am walking quite slowly and am not sure why, so will see my GP on Wednesday. It may be because I came from holiday last week, or the fact I fell over my son's shoe before I went on holiday. I don't think it is a relapse.

All I know is that LDN does work, when I get the dosing right!

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Sandra L, UK
mid 2004 - Primary Progressive Multiple Sclerosis
Sept 2008 - LDN

I am in my mid sixties. I was diagnosed with PPMS approx 5 years ago. As there is nothing to help PPMS at this stage I was interested to read about LDN and I went through to see Dr Gilhooly in Glasgow in the Autumn of 2008, to find out more about this drug.

I decided to try LDN. I now take 3.2ml daily along with various supplements prescribed by Dr Gilhooly.

The first morning after taking LDN (1ml) the night before, I walked unaided from my bedroom downstairs and into the kitchen. The distance is 25ft to the top of the stairs, down 15 stairs, and then approx another 40ft to the kitchen. This however, did not last.

On several occasions since starting LDN I have been able to climb the stairs quite easily without having to pull myself up with the aid of the banister. This only happens now and then. There is no benchmark for me to know what I would be like without LDN.

I still walk short distances with the help of my three-wheeled trolley. If I have to go a distance I need my wheelchair.

I may be a lot worse without LDN, but I do not know what the progression would have been like.

Shane – Anon, UK
2005 - Multiple Sclerosis
March 2008 - LDN

I'm nearing 70, a female from southern Ohio in the USA. I've been active and worked all of my life, retiring from pharmaceutical research the month prior to 9/11. I retired because my age was catching up with me, so I thought. In reality I was progressing with MS.

Twenty years ago I began with slight tremors and I attributed those to a probable sugar imbalance. As time passed, extreme fatigue set in at unusual times, short term memory became a major problem, I was losing a great deal of my vocabulary, my mind was foggy, and I lost the ability to reason as I once could.

Other 'unreasonable' symptoms began and no physician could 'understand'. Then, for no apparent reason, I began to fall and have eye soreness and pain. My ophthalmologist considered MS and took it from there. My neurologist came into my life and ordered Copaxone. I continued to worsen, mentally at first, and then physically.

I gave up my home, my cat, my car, and moved to an assisted care nursing facility. I put myself on the DO NOT RESUSCITATE list, and waited... I had been ambulatory with the aid of a walker but at that point I knew a wheelchair was about one week away and I really did not care anymore... resignation had set in along with hopelessness and numbness.

I had not been able to read for quite some time, however a strange thing happened. I picked up a periodical I didn't even know I had, saw an article on LDN and began to read. I used my pharmaceutical experience and began researching. The more I read, the more determined I became.

I understood the FDA approval for another indication, I found few, if any, adverse events and it seemed to be a very safe possibility. The nursing home physician would not consider prescribing naltrexone since it wasn't approved for MS, so my next step was my neurologist... I handed him copies of my research, he read it and he wrote the script. I took it, and the rest is history.

That was March 2008. Within five doses (5 days), I was coming out of the fog and it only got better from there. My attitude changed, my mind cleared, I found some of that lost vocabulary (note the word 'some'). I began to read and reason again.

Within three months I was walking without a walker or cane. I took myself off of the DNR list! I still have RRMS and I still have the symptoms of MS, but they are manageable today. I have continued with the Copaxone. I've become involved in my community and was elected president of our resident council. I'm on the go as much as I want, but I don't have the time to do all that I want.

MS is part of my life but I have a life and it is a pretty good one. LDN is giving that to me. The one and only problem I have is paying for it myself. I turn all my retirement over to the nursing home with the exception of \$50.00 a month... that is the extent of my income... rather tight! It will be interesting to see where this compound will be in the next few years! I'm just glad I found it, now...

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Silvia L, UK

Nov 2008 – Primary Progressive Multiple Sclerosis (PPMS)

8 January 2009 – LDN

I'd been having problems with my legs and all sorts of things on my left side for ages. So, when the pain became too much, I finally went to see my GP.

She looked at my legs, realised that one of them was thinner than the other, and wanted me to do some exercises to strengthen those muscles. Not being able to lift my left foot off the ground for more than 8 inches, she concluded that I needed to see a neurologist.

For the last few years I'd been telling myself that I was a hypochondriac and that in my mind there was constantly something wrong. Well, I was lucky to have private insurance at that time, and I got to have my MRI within a few weeks.

Two days later, in November 2008, I was told that I had PPMS and sorry, there's nothing traditional medicine can do for PPMS. Great! So I went home, felt despondent and very sad, and scoured the internet - mainly wanting to find people who were experiencing the same as me.

I read and read and read, but in the end it was a very lucky question that got me to where I am now. Somebody had asked; "What exactly is LDN?" I had no idea, but fortunately, I was curious enough to find and read the answers.

I read the name Linda Elsegood. I read ldnresearchtrust.org, and I came across the book "Those who suffer much, know much". The fact that there was information out there that didn't seem to profit anybody in particular but that was freely given by people who cared about their fellow people was convincing. I asked my partner to find all the negatives he could, and he didn't actually find anything.

I read the book online. I joined the ldnresearchtrust.org, and I got great information about how and when to start (like immediately!). My GP was hesitant to prescribe something she had never heard of and asked for more time. I said that I didn't feel that I had time, as I wanted to halt progression now, not in a few weeks or months.

I managed to get myself a prescription over the internet (e-med) and sent this off to Dickson's chemist in Glasgow. My doctor totally agreed with that approach and since

then she has been giving me all further prescriptions, as she can see that LDN is good for me. To start with, I think she realised that it would do no harm and that seemed good enough for her.

I started taking 3mg naltrexone on 8 January 2009, and stayed at that dose for two weeks, then upped my dose to 4.5mg, and have stayed at that dose since, though with occasional minor adjustments down.

In the first weeks of taking LDN, I felt quite tired, to the point of fatigue, but over the initial weeks, my fatigue improved fairly quickly.

I also experienced increased heartbeats and some pounding during the first week, and if I woke during the night, I seemed to be wide-awake. After one week on LDN I had a strikingly vivid dream of killing two rats with my long handled shoehorn. (Doesn't everybody?).

The first really noticeable improvement was the fact that I wasn't getting leg cramps anymore. I had gotten used to refraining from stretching, as that inevitably ended in a leg cramp. So, when I forgot one morning and stretched, I found that my leg didn't cramp, and I was delighted. This was my first realisation that LDN had changed something in me.

The first month on LDN I had been charting my urine in-and-output for my MS nurse. Urinary frequency was high at 9-15 times daily to the loo, with interrupted sleep from getting up once or twice every night. This interrupted sleep and night symptom had been happening for several years prior to my diagnosis.

Six (6) weeks after commencing LDN I took stock of that symptom, because one day I suddenly realised that I'd been sleeping through for several nights. Daytime loo visits had gone down to 6-8, and I'd begun to sleep through most nights without having to get up and go to the loo. My sleep had improved, so I felt more refreshed when I woke.

My cramps have not come back, and my bladder is excellent, even better than it was about 8 years ago. I still have MS, I tire very quickly, I limp, and I quite happily take a nap during the day. I still sway and nearly lose my balance, but I started taking LDN because I wanted the progression to stop, or at least slow down. I didn't expect symptom improvement and relief, but feel very lucky that I got that as well.

I wish people didn't hesitate so long about LDN. With a no-harm-done drug, wouldn't it be a safer bet to give it a go than to wait until more damage has been done?

Steve W, UK**20th Sept 2001 - Relapsing Remitting Multiple Sclerosis****June 2008 - Secondary Progressive Multiple Sclerosis****19th August 2009 - LDN**

I have been a member of the Mysterious Symptoms (MS) club for eight years, and have been steadily abseiling into absurdity. 'I have had five, three day courses of IV steroids. I was bumped up from RRMS to SPMS about eighteen months ago, was given 70mg of Mitoxantrone, having signed a comprehensive disclaimer and being informed about the potential dangers. I have used Copaxone for the last 12 months, have altered my diet, tried acupuncture, and have basically had the attitude that everything is in play.

Hence, two weeks ago, via a circuitous route, I began to self-medicate with 3mls of LDN daily. Common wisdom suggests taking this between the hours of 9pm and midnight, which is what I do. I have already noticed an overall improvement in my condition and the neuropathic pain in my feet appears to be abating. I have stopped taking tramadol, diclofenac and am down to 1200mg of gabapentin a day. This is remarkable.

My simplistic view of the money/politics of LDN, is that there are words from upon high that LDN is a placebo. There is no financial gain for the suppliers of prescribed MS medication. It would appear that the NHS does benefit financially because the majority of MS treatments cannot be taken concurrently with LDN. Is it all possible that the 'perceived wisdom' of MS treatment to flatten the immune system is misdirected and the opposite action of LDN could be a source of embarrassment to MS 'professionals'?

Would there be any merit of LDN users supplying details of traditional treatments that they have stopped taking and totting up the financial benefits to the NHS? Would this equate to the losses experienced by the drug companies? What is the relationship between prescribers and manufacturers?

Having been pensioned out of the Fire Service, would a cure see me 40ft up a ladder again? I hope so.

Day one - Wednesday 19th August:

It was a sleepy morning as usual, so I missed the postman when he rang the doorbell. On finding a card telling me of his inability to deliver a package, I couldn't get to the post office collection site quickly enough. Although extremely tired, I drove up there at the speed of light (well, 'light' exaggeration) to collect my early 'Christmas' present.

Being a bull in a china shop, so to speak, I decided to head straight on in and begin at the top dose of 4.5mls. My logic being, I'll start at the top and work down. I am very robust when it comes to taking drugs. The little bottle, rubber stopper and syringe were a bit of a rigmarole to begin with, so we decanted three 4.5ml doses into some specimen pots I had lying around (not used of course). I decided I couldn't wait and

gave in at 7pm, taking the first dose which tastes like Benylin, for those of you who are playing 'what does it taste like'.

First morning after:

I slept pretty well. My feet didn't hurt as much as usual and I had boundless energy. Having completed 4 days chores in 6 hours, I reached for the decanter at 7pm. The effects were less marked the following day, and I did not sleep as well as the previous night.

I kept to this routine for five days and nothing 'orrible' appened, but my usual symptoms were returning and I was not sleeping well. 'Herself' informs me that my mood and general demeanour were improved. I was finishing suduko puzzles and for the first time in years, I finished the big crossword in the Daily Facist. A little more joint research suggested 3ml between 9pm and 2am, so drinkies took place a little later, around 9pm.

This new regime changed some well practiced night time symptoms, such as 'burning feet' and leg stiffness. I have started sleeping better. I tend to get 7 hours and even by my standards, the dreams are weird. I have always dreamed in colour, so for somebody who normally dreams in black and white, it might come as a bit of a surprise.

Overall, during the last fortnight, I have experienced general improvements in mental abilities, neuropathic pain, mood and energy levels. As yet, there is no marked increase in my mobility. I have started coming out of a relapse, which I think may have been caused by Pig Pox (swine flu).

As we know with MS, it is difficult to know and understand why and how things are happening, but I do believe that I am coming out of this relapse as a result of taking the LDN.

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Steven F, UK

2007 - Primary Progressive Multiple Sclerosis (PPMS)

November 2007 - LDN

My story started 10 years ago when I was walking along and suddenly, my right leg stopped moving.

I went through several 'specialists' who thought I had blocked arteries, rheumatoid arthritis, then trapped nerves (for which I had an operation on the spine), and several other complaints which I cannot even remember the names of now.

Finally, in early 2007, I was diagnosed with Primary Progressive Multiple Sclerosis - after 5 years of various tests and misdiagnosis. I have a particularly painful version of MS, and the pain control has been the most difficult to deal with over the years.

Having spent 25 years soldiering and being very fit, it was deeply distressing, and depressing, to find myself getting weaker and unable to even do basic stuff in the garden. The MS seemed to be progressing at a faster and faster rate. The prognosis for all PPMS is not good, and all the neurologists agree on is that there is little they can give to help or relieve, other than standard pain killers and muscle relaxants.

In June 2007 I was given a heavy dose of steroids for 5 days which did not have the expected effect, so I was given a further 5 days worth. The end result was that I could barely walk and dragged both feet. I could not climb the stairs, and to cap it all I spiralled into depression.

I had reached a particularly low point where the disease seemed to be progressing rapidly and I was using the wheelchair more and more. I had one at work and another for home, just waiting for me to climb into it.

I'd been reading up on LDN for some time, but had been unsure of this unproven treatment. I decided to try it after reading of several other users whom it had helped, figuring I had nothing to lose.

I went to my GP, and he requested guidance from the neurologist, who unequivocally stated that "under no circumstances should I use it." It was this statement more than anything else that made me decide to at least give it a try.

I investigated all the normal methods of obtaining this drug, which incidentally is widely used in other areas of medicine, but no GP would prescribe it for me, and the neurologist treated my request with contempt. I eventually managed to get it on a private prescription via a Harley Street doctor and sent for it via a pharmacy in London.

I started using LDN in Nov 2007, and the affects were almost instant. I was able to walk again, albeit only short distances, and my fatigue almost disappeared. I could climb the stairs, something had been impossible only a few short weeks earlier.

I noticed within two weeks that I was walking better and did not drag my feet as badly as before, but I was still scared to believe the LDN was really working and refused to go to the doctor until I was really sure. But by the end of the first month I was walking with only a normal walking stick. I was less fatigued at work, and was sleeping better at night.

By the end of my second month I felt that everything had stabilised. Although I knew I would never fully improve, I at least felt confident that LDN did work, and that was a relief. I also had more confidence, especially at work. I moved both wheelchairs to a dusty place in the garage, and that's where they'll stay. I remember thinking, 'whether the LDN will stop or slow the progression of my MS, only time will tell', but I did begin to feel confident that it would.

LDN allowed me to continue working, and it was these changes that eventually led to my own GP, having agreed he'd seen a massive improvement, prescribing the drug for me on the NHS, which saved a huge amount of money.

I have continued to use LDN except for a short period due to having to take morphine to control the pain.

My GP has since retired and I am back to trying to obtain LDN via the internet.

I do not proclaim LDN to be any sort of cure but there are too many incidents of massive improvements for those who have tried it for there not to be something that needs to be looked into properly.

Considering the total lack of any formal medication for Primary Progressive sufferers, and no trials or tests in the pipeline, it is offensive to me that the medical profession will rarely consider prescribing it.

Huge amounts of funding are going into research for Relapsing Remitting, but absolutely nothing for PPMS, so even if it only gives minor help, LDN should be made freely accessible to all.

I'm now just over 60 years old and I continue to work full time.

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Steven N, UK
July 2006 - Multiple Sclerosis
April 2007 - LDN

My 20-month experience with LDN

I have now been on 3mg capsules of LDN for 20 months

I haven't had a relapse or exacerbation in that time and other than existing symptoms returning, especially when I am tired or overdoing it, I feel fine.

Until the medical profession can come up with something better and/or prove that LDN doesn't work I'm sticking with it.

I was diagnosed with Relapsing Remitting Multiple Sclerosis in the summer of 2006. I woke up one morning and found the side of my nose was numb. By the end of the day one side of my whole face was numb. By the time I had an appointment with the local hospital I was losing the feeling in my legs.

An MRI and painful lumbar puncture test (which gave me such severe headaches that I had to lie flat for a week) confirmed multiple sclerosis.

Looking back, I had signs of MS since about 2002 - if I drove long distances I had terrible stiffness in my legs, and numbness in my left hand was put down to a trapped nerve by a consultant.

Before LDN, I had 10 months with no medication and was having a major attack every three months. Then I had an attack of optic neuritis in April 2007 and the vision in my

left eye was permanently damaged. The image is now slightly fuzzy and colours are shifted towards the blue end of the spectrum.

As a lot of my work involves photography (I work as a business journalist and photographer), I had to learn to use my other eye.

Enough was enough!

I went on the prescribed drug Avonex for six weeks in September 2007 and have never felt so rough in all my life. I got to the stage where I dreaded Monday nights - Avonex night!

I used to take four paracetamol before my wife gave me the painful deep-muscle injection into my thigh (she's a GP) and would sweat and shiver myself to sleep. One night I took four Mucron by mistake and almost shook the bed to bits. My wife went downstairs and slept on the floor. I eventually got to sleep about 2am.

Avonex would make me feel ill for two days after the increasingly painful injections. After six weeks I said enough was enough and stopped them.

I felt a complete failure - I had stopped the only drug that the Government would let me have.

I had heard about LDN before I started Avonex, so I renewed my research into what it was and how it worked.

My consultant was neutral on the subject (as I expect him to be). He said there had been no clinical trials and therefore he was reluctant to recommend it. He added he had other patients on it, but didn't really want to commit to saying whether it worked or not.

I eventually started LDN in November 2007 as I felt I had nothing to lose. My GP was great about it and my wife (also a GP) was happy to try it once we researched it thoroughly.

I have to have yearly blood tests to make sure that my liver function is still OK, but there have been no problems.

I finally settled on getting my capsules via mail order from Dickson's in Glasgow after previously having to order them over the counter in my local chemist. This became a real pain each month.

Anyway, what has my experience been like?

- ◆ Am I getting worse? Not much I think. The progression now is very, very slow, if at all.
- ◆ Does it repair existing damage - nope! I still have a wonky eye and have lost some feeling in legs and feet. My legs are very stiff and I have to be careful walking down stairs. But, and it is a big but - it doesn't stop me from leading a full and normal life and I have never lost a day's work as a result of MS. Only through the lumbar puncture to diagnose it!
- ◆ Have I had any new numbness, clumsiness, optic neuritis or bladder problems since starting LDN? Not at all!

While the medical profession may be sceptical about the use of Low Dose Naltrexone (LDN) for Relapsing-Remitting MS, there is strong anecdotal evidence that it works. It also appears to have minimal to zero side effects and is very, very cost effective.

I think the biggest disappointment is that many people don't know about it and there is very little support for structured drug trials - the pharmaceutical industry wouldn't make any money out of it.

Because of this LDN remains a potential treatment for a terrible progressive illness that would only cost the Government a few pounds a month. As it is, the government still recommends the CRAB drugs (Copaxone, Rebif, Avonex and Betaferon) with their terrible side effects and high cost.

It is a scandal!

Until something better comes along I will stick with LDN.

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Sue T, USA

December 2004 - Multiple Sclerosis

Nov 2005 - LDN

I used to live a very active life - walking, youth hostelling and camping holidays with my husband and 4 children. One holiday I fell over - for no apparent reason. Then I had real trouble climbing over rocks. On other occasions I just fell over. The GP said it was a trapped nerve. I had tingling in my hand, and my GP said it was from too much time on my laptop, not an injury, etc.

In 2004 I began to fall over more so my husband accompanied me to the GP. I was then referred to a neurologist. He diagnosed MS, and said I needed to have an urgent scan and a lumbar puncture to confirm. My parents paid for a private scan, so my diagnosis could be confirmed quickly. He said it was mild, and that he knew loads of people with MS who played golf. (No money/time for golf!!)

Before starting on LDN in November 2005, my mobility had deteriorated dramatically. I had to hold my husband's arm for support when I walked and the distance I was able to walk became less and less. I was also walking around less and less at work. Initially after taking LDN, my mobility improved dramatically.

I had an appointment with my neuro. She hadn't seen me for about 18 months and appeared surprised that I was really struggling to walk. She referred me to Addenbrooks and said they may give me medications.

That's why I stopped taking LDN for about 6 months in 2007. As soon as I found out they wouldn't give me any treatment, I started LDN again. During that time my bladder problems returned, I was very fatigued, and my mobility deteriorated further.

Since restarting LDN, bladder problems and fatigue have reduced, but my mobility is still bad. I can't walk without sticks, and then only a few steps. I use a wheelchair at work. At home I walk using sticks or walls. If I need to go from room to room or hang out washing, etc I use my scooter.

I still take LDN. I get it prescribed online and dispensed from Dickson's.

I still work full-time as a head teacher, but my mobility continues to deteriorate, and I now use a wheelchair.

I think LDN helps alleviate my fatigue.

My Neurologist is anti-LDN and I daren't tell her I'm on it!

I would like to see it available on the NHS. I think I would have benefited from better guidance on dosage, etc.

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Tami M, Canada
1995 - Relapsing Remitting Multiple Sclerosis
April 2009 - LDN

I am over 50 years old, and I was diagnosed with RRMS in 1995.

I've used Avonex, Rebif and Methotrexate over the years, with some success using Rebif.

Last year, we lost our son to cancer. He was only in his mid 20s. During that period, MS symptoms (all of them) assaulted me, and I spent a year away from work trying to wait it out.

I was sent an article about LDN, and after researching it and asking a lot of questions, I proposed it to my doctor.

He agreed to prescribe it for one month and recommended a pharmacy that could compound it.

I have only been on LDN for 3 months at 3mg strength. At the two-month mark, I was able to walk unassisted for an entire day, which I have not been able to do for some time. Other improvements are also apparent but the mobility issue was the most apparent.

My husband and daughter-in-law noticed a vast improvement. I was so impressed that I was anxious to increase the strength to the 4.5mg maximum, but I suffered severe headaches for days and was told when I asked that I increased the dose too quickly. I

am now back to 3 mg until things settle down and I look forward to further improvements as time goes by.

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Tanja H, USA **March 1987 – Multiple Sclerosis** **October 2006 - LDN**

I was diagnosed with multiple sclerosis (MS) in March 1987. I first visited the doctor with numbness and tingling in my lower extremities in December 1986. I was hospitalised December 19-23, 1986 as the initial 'full body' MRI (magnetic resonance imaging) led neurologists to believe I had a tumor on my spine. Even though the surgeon went as far as to mark my back for surgery, additional tests showed I had a small calcified area in my spinal region rather than a tumor. "Yeh," I thought. I was released from the hospital and placed under the care of the first of several neurologists who in time diagnosed me as having relapsing-remitting MS, i.e. by March 1987.

MS symptoms were minimal for the first 7 years. No meds, sometimes forgetting I even had MS. I relocated my home from Northern Virginia to Baltimore, MD in 1991. I still worked for the Department of Veterans Affairs (VA), but I now worked out of the Eastern Area Office located in Baltimore, MD rather than at VA headquarters that is located in Washington, DC. During 1995, my newly assigned job as project manager to a major work effort required me to travel frequently from Baltimore, Maryland to Chicago, Illinois.

Still seeing my then neurologist annually, I arrived in January 1996 at his office for my yearly appointment. He always watched me as I walked from the waiting room to his office. First question out of his mouth was, "Why are you dragging your left leg?" My response? "I'm not." Talk about denial. Zap... one Betaseron prescription coming up as well as one round of intravenous (IV) steroids! By that time, I had remarried and my husband gave me shots of Betaseron every other day. I also self-injected from time to time.

Long story short: From January 1996 - October 2006 MS symptoms progressively increased. Let's see, blurry vision, lethargy, numbness, tingling, burning, spasticity, poor balance, etc. Meds also increased. Steroids (both IV and pill form), Betaseron injections, Depakote, Beta Interferon (Avonex injections), Tegretol, Di-tropan, Macrodantin, Paxil, prescribed support hose.

Oh yeah---one Canadian crutch to two Canadian crutches, to a walker, to a manual wheelchair, to a power wheelchair. My left arm and left leg no longer move much (is that also known as paralysis? The thought frightens me!) and, I took 'early-out' retirement at the end of December 1997. In 2000, my neurologist classified me as having secondary-progressive MS. By 2004, I learned how to type with one hand as the left hand was no longer cooperating. I've gotten pretty good at it although it was quite challenging at first.

My husband retired August 2002 and we moved into our newly built, handicap accessible retirement home September 3, 2002. I found a local neurologist; and, in 2004 I joined a couple of MS 'boards' on the Internet. It was while visiting and chatting with my MS cyber friends that I first heard mention of LDN (low dose naltrexone). Sounded like some pretty good 'stuff'!

I looked LDN up on the Internet and was led to several LDN web sites including one in the United Kingdom. My research showed lots of plusses---only negative I noted was that LDN was not FDA-approved (Food and Drug Administration) at the 4.5 mg dosage--only at the 50 mg dosage.

After 18 months of research, I talked to my husband and indicated I wanted to stop ALL meds and only take LDN. We discussed this desire with my family doctor who asked me to discuss it with my neurologist. That we did and he was not willing to prescribe LDN off-label for me in light of the fact that there were no clinical trials showing the drug to be effective in the treatment of MS.

So, I went to the phone book and called several local docs to see if any would prescribe LDN. Receiving all negatives, I set up a phone consult with Dr. Bihari in New York. Preferring to remain under 'doctor's care' while taking LDN, I cancelled the New York appointment and made an appointment with a doctor at the University of Pennsylvania (I think it was).

I then started calling pharmacies and asked if they knew of any local doctors prescribing LDN. The very first one I called said yes and they were willing to give me the name and number of the wellness center in town that was participating in a study using LDN for autistic children. I finally made contact with that office, went in for a consult late October 2006 and began taking LDN that month. I have been taking it ever since!

I stopped my injections and in time had the courage to stop several other meds. At this time I only take 4.5mg of LDN, Paxil, and Di-tropan! Hallelujah! The progression of deterioration in my central nervous system STOPPED! I have had no new symptoms since October 2006 and none of my existing symptoms have gotten worse!

My most recent MRI of the brain shows no new lesions and the only one noted is on the 'Pons' of my brain stem. Am I pleased? Yes! Am I convinced that LDN is effective in controlling the progression of 'my' MS? Yes! I still see my current neurologist annually. He is not thrilled with the lack of FDA approval of LDN, but he has not stopped seeing me. Some studies have now occurred, but I really don't know where LDN is as far as the approval process is concerned. Truly, it really does not matter to me. I will continue taking LDN even if the FDA never approves it! My long-term goal is to walk again---with or without crutches!

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Tracie Q, UK

I diarised some of my early experience with LDN, so this will be a detailed story.

On 30th July I went to my neurologist ready to fight to get on LDN. She prescribed it for me within a few minutes of my asking (without a fight). She sent me to a local pharmacy that was able to make them for me with just a short wait. They cost me \$10 for a one-month supply. My neurologist said only one other patient in Eastern Maine had gone on them for MS and that was 5 years ago.

On 31st July I took my first dose of 1.5mg LDN at night and only got up once as opposed to 4 or more times every night before. I slept until 8:30, when I usually wake up at 6:00. I hoped this wasn't a one-night thing, but if so, I figured at least I got a good night sleep for the first time in over a year. I was hoping for continued improvement, but wasn't too confident that it would happen. When you've had MS for 12 years it's hard to get your hopes up that anything will work.

I woke 2 times during the second night and only slept until 7:30. When I woke, I had incredible pain in all my joints, which was a new symptom for me, but the pain was gone an hour later. My arms didn't feel as heavy as usual, but I was also tired and 'crashed' around 4:00pm, needing a nap. I didn't seem to have to urinate during the day as much as usual. Being a teacher with summers off I didn't have to go anywhere so I gave in to it and rested whenever I could. I continued to get headaches, which for me was fairly normal.

My third night was another good night, but during the day I was very emotional. I wasn't sure if it was a symptom or stress. The urgency to urinate wasn't as strong. I didn't feel like I had to rush to the bathroom to avoid an accident. Even though I was getting more uninterrupted sleep, overall I was more tired.

By day 4, urination issues had continued to lessen by the day. I no longer had to go every hour - day or night. Things seemed to be becoming more normal in that respect. When I dared go out without pads, I considered the condition was under control. The tiredness lifted a little, though I still needed to nap during the day. My balance seemed better than 'usual', but my weakness seemed the same. I didn't seem to be slurring my words as much. By emotions were more even so I may have just been stressed.

By day 5 I was up early because I didn't sleep well. I had insomnia for the first part, but still only got up 2 times - 2:30 and around 5:30 am. The urgency to urinate came back around 5:00 pm and went away again by 9:30pm. Does the medicine wear off until the new dose at 9:00pm?

I was having lots of naps so that could have affected my night sleep. One good point was that I was able to walk 8 feet with out the rollator or furniture or walls. I hadn't done that in many months! That was very exciting for me! It was the feeling that I had better balance that allowed me to even try.

Because I fell a lot, I didn't usually go more than 2 feet. The spasticity in my legs seemed not as frequent as it had been. My legs only had a tight feeling once during the night/morning as opposed to 5 or 6 times. I was wondering if the changes were just

from wishful thinking, but hoped some of them would be long lasting, and that only time would tell!

ONE WEEK on LDN and improvements came and went in waves. The only consistent symptom improvement was less frequency and urgency in urination. With the other stuff I had good days and bad days, though I was still sleeping better most nights, I had a few nights of insomnia too. I had heightened emotions on one day. I had better balance on one day. The coldness in my feet went away for a few days. My speech was better for a few days. My arms felt lighter for a few days (when usually they felt like they weighed a ton).

My stamina had not shown any improvement. I still had about 12 'spoons' a day, but my spasticity had improved a little. Weakness in my legs came and went, though my left leg seemed a little better as I didn't have to use my hands to lift it as much and was able to put my left leg on the couch or bed some days without help or as much help. Any change in one week is good, I expect more changes as I am on it longer.

I still had foot drop although that also came and went, and always has. I didn't think I had swallowing problems as much while drinking. My headaches hadn't improved, and I had a headache for most of one week, in the temples.

Having said that, overall, I felt like LDN was helping, and couldn't wait to report progress again after one month.

DAY 31, and after one month on 1.5mg LDN, I noted that I only got up twice during the night and overall I was feeling really good. I seemed to have more energy and stayed up later and I was rarely tired during the day. My moods also improved and overall, I felt life was good!

I noted that after starting my 'period', it didn't seem to make me as tired as it had previously. My arms feel lighter, my balance seemed a bit better, I didn't feel as weak in the legs, and I wasn't choking as much when I ate or drank.

I had a great first week back at work (I'm a teacher). I had been nervous that I wouldn't make it a full day and was wondering how I would survive without a nap, but by the end of the first week, it was like a normal routine and I wasn't even tired! My speech got better as the week progressed, and I wasn't even slurring by the Friday. I walked without assistance a few feet. I had been getting used to using hand controls in my car, but didn't seem to need them as much.

My spasticity had reduced so much I had forgotten to even mention it in my LDN diary! Although there were times when I was still tired, I didn't seem to have to have naps as much, and my vision problems had improved.

I had good days and bad days. Days when I would use only my power chair were followed by worse days trying to walk it seemed, so it seemed nothing had changed.

I should note that during the first month, apart from starting LDN, I also had a lot of stress to deal with. My teenage daughter almost cut off her middle toe stepping on a broken bottle. She cut through toe and tendon, it took 15 stitches to close the wound, and she needed lots of attention and care. Then came the news that they were admitting her to hospital because her foot didn't heal properly, and she had to have an

operation on it. The operation was a success, she got the stitches out, but was in a lot of pain, and she also had to be put on IV antibiotics.

In addition, my husband had an operation on his shoulder during this same period, and I returned to work. I was extremely tired from doing more than usual, because instead of my daughter waiting on me, I was helping her, and I was also preparing my other daughter to leave for college.

After one month on LDN I increased the dose 3mg, and pretty much always took it between 9:00 and 9:30 at night. I found it curious that when I woke at 3:20am (to urinate) I had no symptoms of MS. It was very weird.

I was still optimistic, but wasn't sure if it was a 'miracle drug'.

Past the first month, I began walking around the house without the rollator, and advanced to using my rollator instead of my powerchair at work. I was still having good days and bad days, but more good than bad every month. Before LDN, I was going downhill fast. Now I was not. I no longer needed to wear incontinence pads, and it made a huge difference in my life not to have to worry so much about bathroom breaks and accidents. Although I got tired after a long workday, I wasn't fatigued at work and no longer required naps.

I wasn't choking, and was less embarrassed when eating in public. Most days, my arms had lost the heavy feeling. I was able to move my foot and use the foot brake easier most days when driving. My balance seemed better and I was able to alternate feet when going up stairs. My speech was still slurred, but others said it was better in the mornings.

My gait was not good when walking, and I still couldn't stand for long periods of time. Writing was awkward. My fine motor skills were still affected.

After 1.5 months on LDN, I had laid around the house doing nothing one day and my legs seemed to be worse from not enough use, and I had a little trouble and needed to use hand controls more when driving, but I slept through the night without any 'potty' breaks at all for the first time in a long time.

Over the next few months, symptoms continued to improve, though still in waves, up and down. For example, one day I realised I hadn't had a headache in months, and I was feeling as though the progression had stopped, but I also developed a new symptom: Instead of cold feet, I had burning hot ones! I wasn't sure if it was a side effect of LDN, menopause or MS! Except for burning feet, nothing had gotten worse while everything was constantly worsening the year before I found LDN. I feel like it was a miracle!

I spent the year before LDN going downhill fast, but I diarised that after 3.5 months on LDN, I no longer had daytime fatigue. My arms never feel heavy anymore. I always slept through the night with one pee break at most. My handwriting had improved. The slurring and volume of my voice was still not great, but I no longer choked when eating or drinking. I could alternate feet going upstairs most days. My shower didn't wipe me out for a long time anymore.

I sometimes needed to use my hands to lift my left foot, but this came and went. I needed to use my hand controls for the gas accelerator less and less, and most days I

used my foot for the car brake as well. My energy was pretty good. My spasticity had improved. The frequency in urination had gone way down, but urgency had picked up a little, but I was still able to hold it for longer periods of time than before LDN. I no longer had the major headaches I was having in the beginning of taking LDN, which was a relief. I no longer had mood swings. Overall I seemed happier and felt could always be a lot worse.

Then on 1st November 2008, I went to my neuro for a check in. I had been on LDN for around 3.5 months. By then, nights and mornings were better than afternoons, which I found interesting. Nights were not good before. My ability to drive using my foot had gotten better. The neurologist was pleased there hadn't been any progression in my MS since starting LDN. In fact, she saw the improvements I'd had.

I always seemed to have problems with season changes, so in the week leading up to the appointment, a few things got a little worse: My balance, falls, and urgency got a little worse, but still not as bad as before LDN.

Then in mid November I got a message from an LDN group member asking if my MS was affected by the full moon. I was shocked when I reflected on this, because I realised, the times I always seem to have my worse times each month are around a full moon. She also asked if I had trouble sleeping since taking LDN. I seemed to dream more, but I was still getting 8 hrs of sleep most nights with one bathroom break around 2:30 - 3:30.

In mid January 2009, after 6 months on LDN, I began taking Copaxone along with LDN as a precautionary measure. My daughter really wanted me to do it because I had been going through a lot of stress with my marriage and though my MS had remained pretty stable, I had experienced more bladder urgency that I hadn't seen in many months - though frequency was still down. Everything else seemed the same to me, though I dreamed more than I used to, but as I was MS free in my dreams, I liked them!

My daughter noted in May 2009 that she thought I was experiencing more stiffness in my legs. I think they did seem stiffer, but I'd heard that can happen. Someone suggested LDN could be taken in the morning but I take mine at night.

I hadn't updated my diary for a while because everything was going so well I forgot! Things had improved like bladder and fatigue. My stamina was much better. I slept through most of the night and it was wonderful! One time was the most I got up, and it was almost hourly before LDN! I am almost 'normal' in the amount of times I go a day!

I didn't plan to ever go off LDN! I did use Copaxone for a while too, but more for family members than because I felt I needed it. I guess I saw it as a back-up that wouldn't hurt.

I felt stronger most days although the full moon, once I took more notice of it, did seem to affect me - weird I know. Also, on 'those' 3-4 days each month, my MS was horrible.

After 11 months on LDN I wrote, 'I have been on LDN 11 months now and I think it has saved me!!! I started using a treadmill and did 11 min. If you had told me a year ago I would be doing that I would have said you're crazy! I am so happy with what LDN has done for me. I have vivid dreams at times, but I sleep well and it gets longer all the time. I do have spasticity but it is a small price to pay for bladder control and the halting of the disease.'

When I looked back at my profile, I noticed a major decrease in symptoms after starting LDN. I had gone downhill a lot right before starting, then I saw a major decrease in symptoms, but then my daughter's hospitalisation sent my symptoms skyrocketing again and then I returned to LDN 'normal' and have slowly decreased symptoms since then.

The most noticeable to me being bladder control, less choking and more recently, improved speech. When you live with it day-to-day it is hard to remember the changes because they are so gradual, but I am now able to drive with my feet, not hand controls, in my van (because my feet remember what to do and do it)!

It is now September 2009, and I have been on LDN just over 12 months. Recently, the urgency with my urination has increased and my foot drop is a little worse. Other than that, things are normal!

I am back working from summer vacation, so fatigue may be a factor! I decided to stop using Copaxone.

I am now using a treadmill 10 times a day for 3 min each, but I stress, I built up to that very slowly. That may not sound like much, but after being in a wheelchair it is wonderful. I am sleeping through the night almost every night. I can survive on less than 8 hours sleep and not get tired! LDN has changed my life!

To everyone who is just starting on LDN, I say give it 3 months at least. That is what I was told! I'll never go back to using anything else. I only need incontinence pads as a precaution when I leave the house now. I rarely have accidents, much better! God bless all living with this disease and 'Good Luck' all!

Vickie A, USA
December 2006 – Multiple Sclerosis
August 2007 – LDN

I had a sudden onset of symptoms beginning April 26, 2006. Most notably was the girdling or MS hug. I was misdiagnosed by a GP but eventually referred to a neurologist. I had test after test, including MRIs, and was originally told I had a syrinx. This didn't feel right to me. I took my MRIs to a neurosurgeon who told me I had transverse myelitis.

My symptoms continued to progress so I had a lumbar puncture and in December 2006 I was told I had MS. In January 2007 I started on Rebif.

Over the course of the next seven months my physical condition deteriorated. I had to take naps, sometimes on the floor of my office. I didn't think I was going to be able to continue working.

I felt as though I had a large boulder on my shoulders. My lifestyle had become increasingly limited and restricted by extreme fatigue. I shuffled along slowly. I used a cane if I had to walk any distance. On the rare occasions I went to the grocery store I had to use the carts, so I had begun 'shopping' for an electric cart because I couldn't walk.

This was a very difficult time for me. I'd spent twenty years in the military and was very fit mentally and physically. During all those years I was always the person others had a hard time keeping up with when walking, but I'd reached a point where I didn't feel like doing much of anything. I'd go to work, come home, sit for a little while, then sleep.

I wasn't getting anywhere, and my first neurologist didn't listen and didn't seem to care. Once I made up my mind to discontinue the CRAB medication, I cut my ties with the intent of going it alone.

In July 2007 I stopped taking the Rebif. I just couldn't bear the thought of another shot. As each day passed I felt stronger and stronger.

Then, during my travels over the Internet I came across the low-dose naltrexone treatment (LDN). I was intrigued. I had a good doctor but he appeared to be influenced by the Rebif people – and he certainly wasn't open to alternative medicine.

I took a leap of faith on 1st August 2007 and started LDN. I'd read a lot about LDN. I was hopeful it'd halt progression of my MS and I also hoped to benefit from symptom improvement.

During the same period I also tried Prokarin for a very short time, but I found it too difficult to work with and stopped taking it.

I now go to the Veterans Administration for my MRIs and medications. I have not discussed my taking LDN with the VA. I'll raise it after I see the results of the MRI at the end of the year.

My condition has improved greatly. If nothing else LDN has increased my energy level. I think it also helps me sleep. I've been able to cut my use of Baclofen and Lyrica in half.

I had MRIs of brain, cervical and thoracic spine in December 2007. The neurologist told me that the lesion over T8 was inactive, no change when the contrast was introduced – and there were no new lesions in my brain.

I've also found an ecological internist. She's started me on high doses of D3, shots of B12 and a box full of supplements. I was tested for allergies and have been working hard on cleaning up my diet.

I'm not 100% yet but I work all day with no problems. In fact I feel like I'm more productive. I can go out with friends. I can stay up late, like a grown up! I can go shopping. I can walk my puppy.

Now I feel like I've got my life back I want to tell everyone who might benefit about LDN. Some people are very receptive, others not so much. But I figure if you plant the seed, when they're ready they'll remember. Low-dose Naltrexone has given me my life back so I'm sharing my story in the hope it'll inspire and benefit others.

UPDATE: July 2008: Changed from liquid LDN preparation to compounded capsules. Also switched doctors. The new doctor is an M.D. who runs a clinic offering infrared sauna, acupuncture and other services. I am starting chelation therapy in a week to reduce my heavy metals load. I'm still benefiting from LDN and will continue to take it.

UPDATE: July 2009: 3 years later and I'm still taking my LDN, and I've also done 18 chelation therapy treatments.

I went back to Hippocrates in W. Palm Beach Florida in March 2009, and spent three weeks doing wheat grass, juices, raw food diet, mineral pool, infra-red sauna. I did great.

When I came home I purchased a portable infrared sauna and a dehydrator. I'm juicing daily. I also started seeing a true osteopath in town. I believe he is helping me a great deal. I'm doing manual medicine treatments and also attending a healing circle two or three times a month.

I'm being very proactive about my health, and it's paying off.

Vicki F, USA
1998 - Progressive Relapsing MS
October 2005 - LDN

This was written by my best friend, my nurse, in September 2005. Nurse Judy saw me daily, weekly and saw what was happening to my life.

' ... My friend Vicki is a vivacious, articulate, beautiful, fun-loving woman. She is the woman I see and know today. She is not the same woman I knew a year ago. Vicki has Multiple Sclerosis and has struggled and suffered for the past 10 years or so. Her life has not been easy, nor that of her family.

I first got to know Vicki around the time she was diagnosed. I remember how devastating that diagnosis was. She was determined to stay active and to fight its progression as much as she could. She did all the 'right' things, took the prescribed, medically accepted medications, and hoped for the best. Unfortunately, over time she continued to deteriorate.

For five years, up until almost a year ago, she took Avonex injections weekly, another form of standard treatment for MS. I'm a Registered Nurse and administered those injections every Monday night. She continued to deteriorate. I watched for 5 years as my beautiful friend became weaker and weaker and grew mentally more confused and forgetful.

Vicki often arrived at my home on those Monday nights dragging her leg, rubbing her thighs due to nerve pain, unable to stand for more than a few minutes, and often in tears. It was heartbreaking. Being a nurse and having taken care of patients with MS, I knew what most certainly lay ahead for her. It was not a future anyone should have to face.

When Vicki first spoke to me last Fall about the possibility of taking LDN, a drug she had researched, but which was not a mainstream treatment for MS, she was very excited but also very afraid. What if she gave up her traditional treatment for this and only got worse? It was an unknown. But what was known, was that after 10 years of standard treatment she was most definitely getting worse. And for the past year the decline was increasing. So, she took a leap of faith and hasn't looked back.

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I went to the doctor in 1996 complaining of some tingling and numbness in my arms and legs. In 1998, after two years of testing, I was finally given the diagnosis of Progressive Relapsing MS. By then my symptoms had worsened; balance, memory, speech, sensitivity to touch, spasms, extreme pain, fatigue, bowel and bladder problems and various other symptoms of MS had become my way of life.

We were given information about some of the different therapies that they were using for MS. We came to the conclusion that we would try one of the ABC drugs, Avonex.

Later they added another injection, Copaxone, and the group is referred to now as the CRAB drugs. I began the weekly injections, which for the 9 years I was on them had horrific side effects - flu-like symptoms, fever and chills. I stayed on Avonex for the next six years and was still progressing at a rate that I felt was alarming.

By the end of my time on Avonex I had spent most of my time in bed or on the couch. My pain was unbearable throughout all of my body and I decided to start trying other drugs that some MS sufferers were finding relief with. Neurontin, Baclofen, steroid infusions and a list of other medications that would fill this whole page, not to mention two infusions of Tysabri before it was pulled from the market in 2005 for causing a rare brain disease resulting in death.

The MS was still progressing over the years, so my doctor decided Avonex had run its course and they changed my injections from Avonex to Copaxone. The side effects from the Copaxone eventually put me in hospital. No longer able to tolerate the Copaxone, I started Rebiff. The Rebiff turned me into a mental monster, not only was I hating life and everyone around me but the progression and pain of my MS was becoming unbearable.

The last six years were spent on vicodine. I was taking 10 to 12 10mg tablets a day. Because of the high doses of codeine my doctors thought it best to start using the morphine patch. I then became allergic to morphine, so it was on to Oxycotin. I spent the following years in bed or on the couch, as this was the best way to cope with the pain, hating life, and depression.

I had to give up my greatest passion, golf. I could not even ride in the cart. My husband riding over the smallest of bumps would send even more pain throughout my whole body. Before the second hole he had to take me home where I would go to bed and cry because I no longer was able to endure such a simple task. It's funny how we take the simplest of daily tasks for granted.

In October 2005 my husband, the biggest sceptic of all, came across a drug that he had read about on the Internet called LDN (Low Dose Naltrexone). After some diligent research on the drug we decided that I had nothing to lose, and some of the stories that we read from others who were on it were very inspiring. Naltrexone is an opiate antagonist used effectively in rehab centers for the treatment of recovering heroin addicts and alcoholics, but for this treatment, less than one tenth of a dose and a tiny pill was all it would take to stop or slow the progression of my MS, with no side effects. I had to try it.

You can't have any opiate-based pain medications in your system when starting LDN. I had to detox for two weeks. Those were the hardest two weeks, horrible shakes, sweats, and crawling skin. My only thought was this had better be worth it.

I started on LDN at the end of October of 2005. I felt an improvement within two days. My energy level was amazing. Still unsure of what was to come, I continued the LDN and kept my fingers crossed.

By the end of 6 months I was pain free, the numbness and tingling were gone, my memory had improved, my balance and walking were no longer a problem, and other problems I had developed were gone. I was loving life again, my family, friends and myself. I was no longer on any medications except my vitamins and my LDN. I was,

after 9 years, no longer on any anti depressant, and I was truly thankful I'd found LDN when I did.

Another year and I would have had to use a walker because I was losing strength and the will to walk.

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Update from Nurse Judy, September 2007

"Nothing short of a miracle", is a phrase that aptly describes my friend Vicki. Diagnosed 11 years ago with MS, the ensuing years have been physically challenging and mentally devastating. Living with a chronic, debilitating disease that over time eroded and completely changed the person she was would be enough to make most people give up. But, Vicki continued to hope SOMETHING could be found to help her.

After years of belief in standard medical treatments, even in the face of continued deterioration, four years ago Vicki made the very difficult decision and stopped all currently approved medications. Years of horrible side effects had taken their toll. She had heard about and investigated the treatment of MS with low dose Naltrexone, which was being used off label and seemed to be helping people with few or no side effects. As Vicki's 'nurse friend', she asked my opinion as an RN and someone had in fact given her weekly shots for five years, and couldn't deny the fact that she was much worse than she'd ever been.

So, my advice was, why not try what just might give you some quality of life. In the past two years I have seen a transformation that really is a 'miracle' of sorts. Vicki has gone from a woman who lived with constant pain, usually couldn't walk without dragging her right leg, was exhausted, unfocused and at times confused, to someone who is unstoppable! She is clear headed and articulate, requires no pain medication, can walk miles and still have energy and has a zest for life I last saw in her 11 years ago.

The person I see today is so incredibly different. She can't get enough of life. She has a passion and a zest she never had. More importantly, physically she's unstoppable. Life used to consist of many days of getting from bed to the couch and back again. Today, you can rarely catch her at home. She has energy, she's virtually pain free, mentally she's sharp and clear, and on her MRI, some of her lesions are changing.

Will this last? Who knows? There are no guarantees in life for any of us. We have to take advantage of the time we have. I do know that had she not done this, she would have been headed down a dead end road. My hope and prayer is that she will remain healthy and strong and continue to light the world with her radiance.

She truly has found the self she lost! She's even considering going back to work, something that was totally unthinkable two years ago. I cringe to even think where her life and health would be today had she not started the Naltrexone. My prayer for Vicki is for continued good health and many more years of all life has to offer.... '

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My Update July 20, 2009

By March 2008 I hadn't been to the ER, and I hadn't had to visit my doctors every other month. I hadn't had an attack, nor was I on any medications except the vitamins and LDN. What did I owe it all to? Ask the LDN. I was back playing golf, my energy level was amazing, and I was no longer in the horrific pain I once lived with. YES life truly was good once again.

It is now July 2009, and I still keep asking myself, 'Why don't more people know about LDN'?

Then I ask myself, 'why doesn't our government do more to provide funding for research for drugs such as LDN, and why aren't there more drug companies funding research for such a 'wonder drug' that has helped thousands around the world'?

October of 2009 will mark my 4-year anniversary on LDN. What a difference it has made, I'm back to work, no longer on disability, haven't been in the ER, and have saved my insurance company a lot of money! And most of all I am able to help others once again. Sure, I get tired once in a while, and a little achy, but only if I forget and eat junk or don't get enough rest.

I still have MS, but it no longer controls my life. I no longer take the costly, invasive injections. I don't miss the years of weekly flu-like symptoms that I had for 6 years when taking Avonex, when I felt horrible, weekly. I don't miss the morphine, Norco, Oxycontin, the fatigue, pain, and countless nights of sleep I would miss because it hurt so bad to lay down.

The brain fog is gone, the feeling of self worth is back, and I owe it all to a drug that Dr. Zagon discovered by accident in the lab years ago. Dr. Zagon is a brilliant scientist and we can't afford to ignore his research any longer. Our economy, government, and doctors need to know what LDN is and what it can do. We need to bring this inexpensive, off-label drug use to the front of medicine, where it belongs.

Too bad LDN can't make huge profits, everyone would be on it and the drug companies would make it, and well, let's just say they would all be flying private jets.

I'm grateful to Dr. Zagon, for the discovery and to Dr. Bihari for having the interest in reading the research and thinking about us, the patients, instead of the interests of the drug companies.

**Wanda L, Canada****June 2006 - Fibromyalgia, Chronic Fatigue Syndrome (CFS)****27 February 2009 - LDN**

Here's my story, quick and to the point.

In June 2006 I became instantly sick. I was diagnosed with Fibromyalgia/Chronic Fatigue Syndrome.

I reacted to all the drugs that are supposed to help, so I swore I would never take those awful pills again and would fight this thing in other ways.

Some helped, but my joints still ached and 'creaked'.

When I learned of LDN I went to see my great doctor, who thought, 'why not'.

I'm still only on 3mg LDN, but I have to say that I feel GREAT!

I have my life back, and I am so appreciative of that I want to share LDN with the world, as we all do.

My moods are much improved, and I have crazy improved self confidence. It gets so much easier to make healthy lifestyle changes when you are on LDN... at least that's what I've found. There is no pressure.

Pretty soon I'll be increasing my dose to 4.5mg, so I will know more when October 2009 rolls around. In my city of there are only 4 people on LDN, yet our province has a high percentage of MS cases. The ignorance must be stamped out and the sharing of knowledge given birth!!

# 97

**Wendy – ANON, UK**  
**2000 - diagnosed - Multiple Sclerosis**  
**July 14 2009 - LDN**

I will be seventy in October and was diagnosed with MS in the year 2000.

I have a slowly progressive form of the illness, which was treated only to alleviate the symptoms.

I wasn't happy with the results from steroids or Mitoxentrate and researched LDN on line.

Having spent six months trying to persuade my neurologist and my GP to prescribe LDN on the NHS I contacted the LDN Research trust. I decided to go on line and fund my medication for a trial period.

On July 14th this year I started taking the medication and within the first month my balance and co-ordination improved.

I felt the grip in my right hand tighten and had far more energy.

The only side effect was a brief disturbance to my sleep pattern.

I am into my second month now and my mobility is noticeably improved, I have managed to resume doing some gardening and can walk for thirty steps without any aid. My previous record was twelve and I hope to improve still.

# 98

**Zillah B, UK**  
**Mar 1994 - Relapsing Remitting Multiple Sclerosis (RRMS)**  
**November 2006 – LDN**

I was diagnosed with MS in March 1994. I was told that stress was probably the trigger and working six days a week for about 10 hours a day didn't help.

I was not ready for this news and after a course of steroids helped me to fully recover from my episode I felt sure that I could carry on working the same 10 hours a day.

I was wrong! Approximately two months later I relapsed yet again and was quickly taken back to the hospital. I learned I had Relapsing Remitting Multiple Sclerosis

(RRMS), and was provided with a wheelchair from Scope and told to expect to be using it much more within a year. This was also very unwelcome news.

After my recovery the second time, I decided that using the wheelchair sooner rather than later was not going to happen and I started to learn to manage the situation.

The symptoms I experienced were numbness and weakness in my legs, and some tingling in my arms. Providing I didn't overdo it and rested if I got fatigued, I seemed to do fine.

On the whole, I feel I managed the MS well over the years, although there were times when I felt despair because I was so young when it first presented, just out of my teens, and I felt it was so unfair this had happened to me.

I've had MS now for 14 years. I've had some relapses during this time - some more frequent than others - and various symptoms.

I've had relapses and they've typically occurred around major events in my life; such as moving house, redundancy, and preparing for my wedding. This taught me stress and anxiety play a major role in the occurrence of relapses, however; on my actual wedding day, my health was very good (probably the good adrenaline!).

A couple of years ago I had a relapse. The steroids didn't help recovery anywhere near as much as they used to when I relapsed, so I decided to see if there was more that could be done - rather than dosing up on steroids, which no longer helped me.

I asked around, and a friend told me he had heard about something called High Dose Oxygen Therapy (HDOT). I did lots research, made some enquiries and found The West of England MS Therapy Centre in Nailsea, near Bristol was offering the therapy.

I was very surprised to learn the centre was established way back in 1985, to provide support, advice and therapies for people with MS - also that they were one of many such centres around the country! Why aren't all patients with MS informed of this?

I went to the centre every day for three weeks. This is the recommended 'saturation period', and it also helps practitioners determine the best treatment level for each patient. I started noticing some lessening of fatigue after the first week, but my balance and mobility were still a problem. After the second week, urgency to go to the toilet considerably improved, and my mobility also began to improve.

For the first time in as long as I can remember, I began to sleep through the night without needing to use the toilet. I felt the oxygen was definitely helping. I began attending the centre regularly, for one or two sessions a week, and was very surprised by how many visitors used its facilities.

While attending the MS Therapy Centre I chatted to others with similar problems. Most were using the HDOT, but some were also having other therapies the centre offered, such as physiotherapy, counselling, reflexology and aromatherapy. The centre offered all their therapies at low 'donation prices', and I thought, if they helped MS sufferers it was definitely worth it.

I also learned of another medicine that was said to help MS - an alternative to Beta Interferon which, I'd been told, was not justified for my level of symptoms and

progression. I found out that, although not readily available in this country LDN had been used in the US for many years to help MS sufferers.

Other people at the centre were taking Low Dose Naltrexone (LDN) with good results. I'd never heard of this before, so I researched further. I discovered plenty of information about the medicine from the internet, particularly from the LDN Research Trust website. I must say, I owe a big debt of gratitude to Linda Elsegood who owns the site, and Dr Bob Lawrence, because both helped me learn more about LDN.

I found a doctor who was familiar with LDN, and gained a prescription. I was monitored carefully by him throughout my first few months.

I started taking 3mg and continued that for the first month, then moved up to the optimum higher dose of 4.5mg and have been on that dose since. I've been taking LDN ever since.

Although at the start I noticed some minor re-occurrences of old symptoms, such as tingling in one leg, I'd been forewarned this could happen and so wasn't worried. I just waited patiently for it to pass.

I felt the LDN was definitely helping to stop me from slipping back. In fact, my health continued to improve and the initial recurrence of symptoms dissipated soon after.

In terms of improvement, in a reasonably short period of time I no longer had an urgent need to go to the toilet, my energy and mobility greatly improved, and although I still had some difficulty with balance from time to time, even that was slowly improving. Fatigue was no longer a big issue, as long as I was realistic and sensible.

For me, the combination of LDN and Oxygen Therapy was the key to my feeling so much better, on more fronts than I had in years.

Over recent years, my life has undergone some fundamental life-changing events.

The first was on Boxing Day 2006 when my stepson complained about discomfort in the hip and his mobility was affected. My husband ended up spending a couple of hours with him in casualty. He was scheduled for a follow-up hospital appointment in early January 2007, but none of us suspected how serious his condition was, not even the hospital staff.

After his tests, and quite suddenly, everything changed. He was suffering from a very virulent form of Cancer of the ligament, which is extremely rare. An oncologist was called in.

Both his mother and my husband took it in turns to be at his bedside - my husband usually there all night. I visited as much as I could, but the shock hadn't done much for my health. In fact, both sides of the family were regular visitors to his bedside. The way he dealt with this final illness, at only 14 years of age, was truly inspirational, but sadly, it claimed his life only 4 short months after being diagnosed. You can imagine our feelings at his loss.

My husband was devastated, and although I tried my best to support him he was unable either to share his grief with me nor witness evidence of my own personal grief. Unfortunately he became more and more distant, spending more and more time away



from home. We eventually parted, without acrimony, just before Christmas 2007 when I finally made the move to live geographically closer to my family because my health was now suffering considerably. I spent a short while living with my mother until I felt able to move into my new home.

Even though I experienced 3 major stressful events over an extended period of time - bereavement, a marriage break-up, and moving house (twice) - I did not end up in hospital. I'm convinced, if not for LDN, I would have been in hospital and on steroids. These 3 events, so close together, did cause a relapse, but nothing as bad as one would expect under these circumstances.

I've recently been working on building myself back up again; and on the positive side, I'm now able to work four days a week (2 in the office and 2 from home).

I've been seeing a physio and it's helped with mobility, but unfortunately I can't take additional time off to go for oxygen therapy. I'm more tired and getting aches and pains, and in particular, the pins and needles have become more pronounced, so I plan to go back to Nailsea and resume the oxygen therapy. I feel the LDN and oxygen therapy combined may work better for me while I'm trying to rebuild myself.

It is now 14 years since I was told that I would be in a wheelchair within the year. Although I use a scooter to walk the dog (he's a collie and needs a lot of exercise), and I occasionally use the wheelchair when shopping (e.g. for clothes), on the whole I'm still using my own two feet; even though I sometimes use crutches.

My experience has also helped others. A friend and colleague's wife was recently diagnosed with MS and immediately came to see me for some advice, because they felt I was doing quite well.

I wish I'd heard about LDN earlier. There isn't a cure for MS yet, but I'm convinced that LDN is a great help in minimizing its impact.

Update - August 2009: I don't really have any additional information or events since the last update I sent you. I am still taking the LDN, and it is still helping. Not a lot has change since the last update, I am still working 4 days a week and living in my own house.

**Zoe K, UK**  
**2006 - Crohn's Disease**  
**late 2007 - LDN**

In 2006 I was diagnosed with Crohn's disease.

It started with a chicken leg and a classically English BBQ. I found the host sheltering under an umbrella with a disposable tray of coals, guttering under the weight of tepid food. Later, to be polite and because I worked as a cook, I took one bite of the chicken before realizing it was gelatinous and raw at the bone.

Four of us came down with food poisoning that night and it was only me that didn't get better. Six weeks later after losing a stone and feeling that something wasn't right, I went to my doctor. The antibiotics didn't work but then I became one of the lucky ones so to speak medically. After a colonoscopy, I had an instant diagnosis of Crohn's disease, or in gruesome detail, ulcers were spreading like chicken pox along the entire length of my gut.

At first, I felt vindicated, there was something wrong with me and I wasn't being pathetic, as I'd felt before. But if I had the label, so too did the doctors and therefore there was treatment. Prednisolone was mentioned, not as a choice but as my only option and so I began what they told me would be one month on and one month tapering. It helped, I realized I had energy, I wasn't continually on the toilet or writhing in pain, and as someone obsessed with food, I had my appetite back

It was great if I discounted the manic highs and lows, the not really sleeping and the breakout of spots on my face. Which, at first, I did thinking this was necessary. The month passed and I began to taper the dose. As the mg's came down, so too did my weight, my appetite and my mood. And so began the yo-yo. I was on steroids for over a year and a half. The doctors tried to get me to change onto something more long-term, but now I didn't trust it. I looked twice at the possible medications, after all, this one hadn't worked out like they said. For all my life I had perceived doctors as infallible, and now I realized with the best will in the world - there is much that they don't know, especially in the arena of chronic disease.

Everyone had advice and worse, warnings about what to eat, what not to eat, and their own prejudices about doctors, treatments and medication. Navigating it all was a sea of confusion with a foggy steroid-filled head and gut instincts that were decidedly queasy. I tried diets. I tried wormwood. I banished all yeast from my life (nigh on impossible). I reverted to babyhood and drank only white liquid from a tin, even though as a baby I had rejected anything but the breast.

One of the topmost Crohn's specialists in the UK said this was the best option and so for 6 weeks I blended my morning tin of nutrient milk shake and carried a flask, trying to convince myself that chewing was over-rated. Then came weaning food back in, more difficult than the first time for sure, especially as my health was worse than at the start. Food went through me in less than four hours. I timed it. My life shrank and was

consumed by the disease. I shrank too. My weight changed daily. For a few weeks I'd gain weight and skip around thinking it was all over, and then the bottom would drop out or as I started saying with a wry smile to anyone who'd listen, the world dropped out of my bottom.

My starting weight was around 10.5 stone, I'm over 5' 8". It dropped to less than 7 stone, a B.M.I of 14. The doctor repeatedly threatened hospitalisation. Having moved back into my mother's house I spent weeks in bed, tended to by my mother and sister. Terrified of eating, but even more terrified of the consequences of being empty. The worst part of it was coping with the cycles, the few weeks of hope and conviction that I was getting better, then it slipping away and the cramping beginning again. Each time was more depressing than the one before, the mental drop crashed onto and compounded the recurrence of symptoms.

The doctors shifted in their tactics. Now, instead of the disease, it was me that was being difficult. I was not accepting the gravity of my situation and ignoring their advice was risking my future chances of health and happiness. By not switching medication, one doctor told me I was signing myself up for a future of bowel operations and pain.

To me, the medications on offer didn't sound so great. Azathioprin, they said, would hold down my faulty immune system with a strong arm to stop it playing up. The other option would coat my entire intestine via 16 pills a day to stop the inflammation. I wondered what benefit could possibly be accrued by further weakening my immunity.

Surely at my tender age, still well under 30, my already battered system didn't need to be messed with? I kept stalling, and the weight kept falling off and with it... my quality of life. Then my uncle, an open-minded doctor in the States had a patient mention to him an alternative use of Low Dose Naltrexone. He looked into it and tentatively suggested it. My GP here was willing, once I presented the evidence.

He said he'd prescribe it and let me trial it, with the condition of weekly blood tests, weigh-ins and the understanding that if it didn't help, I'd play ball with the specialists. Through Linda at the LDN Research Trust, I found Dickson's chemist and received my first batch through the mail. The only concern I had was the side-effect of interrupted sleep, but then I figured, not much could be worse than 10 toilet trips a night.

During the first week my dreams were a little odd, but then I was at least sleeping enough to dream. I continued with the steroid at the same time, and at first, no-one would say which drug was helping. But the blood tests told the story. Each week my inflammation indicator levels dropped down. By week three they were approaching normal, and I was gaining weight, fast.

My doctor was overjoyed. I was too, but the long months of yo-yo-ing hovered in my mind and I waited, quietly hopeful, but at the same time dreading any new downward slope. The blood tests became fortnightly, then monthly. Then, I got the most welcome advice I'd heard in a long time. My GP told me to go away and avoid doctors. I did.

I was lucky enough to have the luxury of taking the time to heal myself. I followed the birds and flew south for the winter, becoming the houseguest that never leaves at my cousin's in Florida. I watched my diet, eating the now familiar soft pappy food and only slowly bringing in new tastes and past loves. I gained weight and strength and most importantly, learned to trust my body again.

It took another year before I looked at salad and popcorn with anything other than distrust mixed with intense envy of the people enjoying it. Now almost two years in, with a tiny 4.5mg pill each evening, I eat what I want and I appreciate every ounce of energy and freedom that life affords me. I know that my gut is a weak point, and if I get run down it acts up, but that is life. Everyone has their Achilles heel, but now mine has protection.

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## **Zora T**

**1983 – Probable MS in London**

**1983 – Definite Multiple Sclerosis Slovakia, Bratislava**

**Sept 2004 - LDN**

This is what I have written on my web page. Yahoo is scrapping geocities this October, so I have to find another place and also to update it.

I have been on LDN since September 2004, 5 years as at September 2009.

I use and prefer taking liquid LDN, so I place one 50mg Naltrexone tablet in 50ml of filtered water to dilute it, then draw up a 4.5ml dose each evening.

Why this method? I have two daughters in Canada and we find it is much easier to get the 50mg tablets. That way, I need a prescription from my doctor only every 3 years or so, and there are no additional fillers to worry about.

Before LDN, I was slowly but surely going downhill. I was reading message boards in Yahoo for a long time before I made my mind up and gave it a try. The most attractive thing was that it was readily available and not expensive.

After a while I noticed that I was not deteriorating as before. I now do not feel fatigued at all, I have more strength in my hands, and I manage to do a lot of other things.

Other than the above I did not notice anything else different about my body.

People say the response depends how long a person has the disease and the damage that has already occurred. I've had MS for a long time, so ceasing the deterioration was welcome. I definitely will not stop this medication.

## ACKNOWLEDGEMENTS

The need to raise awareness of LDN unites us all.

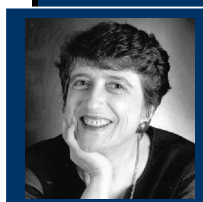
Many have worked tirelessly over many years  
so you too will learn of  
and hopefully benefit from LDN.

In particular, Linda Elsegood  
would like to gratefully acknowledge  
the dedication of the following  
International LDN Awareness Week  
Collaborators who contributed generously  
of their time to support this project in the  
interest of international unity.

### SammyJo Wilkinson of LDNers.org

is an MS Patient Advocate who has been helped immeasurably by LDN, and who has worked tirelessly to raise funding for LDN research and awareness. SammyJo co-authored, with Elaine Moore, the book 'The Promise of Low Dose Naltrexone Therapy: Potential Benefits in Cancer, Autoimmune, Neurological, and Infectious Disorders'. Contact [redtruck99@yahoo.com](mailto:redtruck99@yahoo.com)

### Julia Schopick of HonestMedicine.com



Julia Schopick's website, [HonestMedicine.com](http://HonestMedicine.com), contains information about treatments like LDN, which save lives, but aren't well enough known. Julia compiled the Int'l LDN Awareness Week ebook, 'The Faces of LDN'; she is in the process of writing another book, 'Four Lifesaving Treatments that Could Change Healthcare' (pub. date, March, 2010). LDN is one of the four treatments. Contact [JuliaS1573@aol.com](mailto:JuliaS1573@aol.com)

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PLEASE NOTE  
the primary LDN website  
is located in the USA

Dr David Gluck, Editor, primary LDN website  
[www.lowdosenaltrexone.org](http://www.lowdosenaltrexone.org)

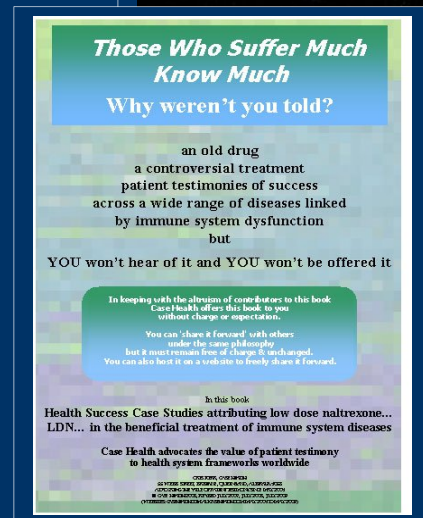
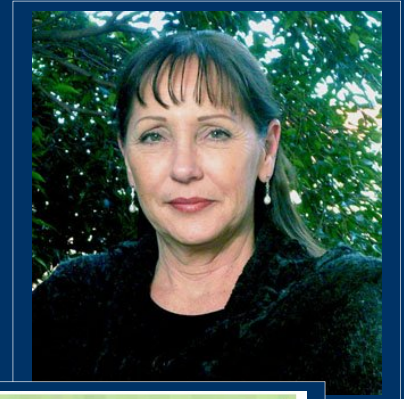
For more information on the USA LDN Conference go to  
<http://www.projectldn.com>

## ACKNOWLEDGEMENT

Content and Production Assistance was contributed by Cris Kerr of Case Health. Cris has long been an Advocate for the Value of Patient Testimony, administering the 'Case Health – Health Success Stories' website from 2001 to 2009.

Cris also produced the free LDN Resource Book 'Those Who Suffer Much, Know Much', now in a 2009 edition which features 47 LDN case studies and interviews with nine health professionals familiar with LDN.

The 2009 edition of the book is now available free of charge or expectation from the LDN Research Trust website <http://www.ldnresearchtrustfiles.co.uk/docs/2009.pdf>  
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