

**Narrative responses to survey on use of high-dose thiamine by
people with ME/CFS, EDS and Fibromyalgia.**

March 19, 2023 (final file)

NOTE: These responses are unedited except to remove information that could be used to identify respondents.

Please share any other information you wish about your experience with high-dose thiamine.

its a balancing act. when I have acute symptoms of spinal CSF leaks and positional headache, I need to avoid large doses of B1. However, large doses might be helpful when the body "overreacts" and overproduces CSF when the leak is healing and not leaking as much. Also, my dr recommended trace amounts of other B vitamins, as cofactors to support high dosing of B1. My blood level B1 were tested by a dysautonomic neurologist, based on my symptoms. The test came back normal to low normal. The neurologist did not mention to me he was even testing. It took me another year to learn that the B1 blood test is designed to catch beri beri level of B1 deficiency, the end of the spectrum.

The amount of research of B1 deficiency in animals, cattle, marine, fish is staggering. Many animals that appear to get disoriented and "beach" themselves or behave erratically seem to suffer from B1 deficiency.

Have taken a few years, when stop leg pain much worse

Migraines from lower doses were vertigo, nausea type

It has helped with light and noise sensitivity.

I used it because I had ME/CFS and had a lot of problems processing alcohol and formaldehyde (which made me really sick), I saw a massive improvement.

One of the most helpful things for CFS/PEM. I could tell it was working the day following the first time I tried a 300 mg dose, then upped the dosage to that based on a study for IBS/Chron's even though I do not have these or symptoms of these. It was just the only study I could find that had dosing based on weight/gender. Thiamin HCL helps, Benfotiamine made me feel worse for several days after trying it.

I found benfotiamine didn't exacerbate my IC pain nearly as much as thiamine hydrochloride or thiamine mononitrate

Seems to enable me to tolerate thyroid meds (synthetic t3/4)

Saw your article on it just over a year ago and tried it. Really happy with results. It's not a fox, but it certainly helps.

I wish I could get it to work again. Imagine going from housebound to playing a bit of tennis. Unfortunately, after a couple of decades my body wasn't really ready for that and I injured myself often. I wish I knew why it stopped working.

Thiamin Hcl I tried at different doses titrating up from 100mg up to 500. I also tried benfo 100 mg. I tried combined, and then tried only Hcl. Both made me worse. TPP is the one that works for me. I haven't tried the lipid-based ones. I have a sense they will only make things screwy.

I still have POTS. I just don't have the symptoms, so I actually have to wear an arm band and monitor because otherwise I would not know until HR and BP get very very high. I avoid going past anaerobic threshold, so by the time it hits 100bpm, it's time for me to lay down. Whereas before my BP and HR were all over the place (hyperPOTS - low pressure, high pressure, bradycardia tachycardia), now I'm only 'stuck with the orthostatic hypertension and the tachycardia. I don't black out anymore and my BP and HR don't drop too low with B1.

While it helps with PEM, I find that the best way to avoid PEM is to pace. B1 helps me pacing, because it brings down the tachycardia and I'm able to be upright for longer. i.e. - I can cook, with breaks or take a shower, etc. Pacing pacing.

It has improved my mental abilities greatly. I would crash from just conversations or thinking about something stimulating otherwise. Much greater mental and mood stability. Focus and memory. Alzheimer's light be gone. For some reason, the Hcl and benfo made these all much worse. I do sleep better, per my wrist band. Increased deep sleep.

High dose thiamin should be supplemented with B2 and... B3 was it? There are numerous studies on this. Dr Lonsdale does stress taking a multi-b and magnesium. The thing is that many have problems supplementing B6 (and don't know it) so multi can be tricky.

I take it with equal amount riboflavin. Do genetic testing for MTHFR! Too much B12 causes fatigue to return! I also can get fatigue that improves with taking amino acids on top of the B vits.

I didn't experience a sig impact with global symptoms but only stopped due to oral pain. Because this was a commercial OTC supplement, I cannot know the exact dose I'm taking because there's a lack of quality control. I plan to try different brands to see if some work better, but cost is also an issue. I've noticed little difference between the 100mg versus 500mg capsules, so I'm not confident about the doses I'm getting.

Seemed to improve carbohydrate tolerance and made me feel relaxed. A feeling that is super rare for me since getting POTS. Effect diminishes after a few days as though my body builds tolerance. Tried other things to improve carbohydrate tolerance / PDH with minimal effect.

I was bitten by a tick in the UK in 2016, and was not diagnosed for almost 5 months. I have been dealing with Chronic or Post Treatment Tick Borne Infections. I was okay before that.

The thiamine has been a game changer, it has increased energy, greatly improved cognition and cleared brain fog, increased exercise and muscle endurance, and improved some random possibly autonomic symptoms. If I could have only one supplement, it would be thiamine. I am currently taking a mix of Lipothiamine, benfotiamine, and Thiamine hcl. I have found that it works best for me when I take the thiamine alone, in the morning with nothing else. For me, taking with other vitamins, even B vitamins seems to decrease the effect.

The dosage I based on the 2020 paper that suggested a weight based dosage. As I'm 96kg, the 1750mg dose seems appropriate.

It helped so much I'm staying on it. My healthy husband (who is normally spectacularly in observant about his own health) volunteered, without even knowing I'd given it to him for a few days, that his memory had improved.

I started taking it because I was diagnosed with Celiac. I was prescribed B2 400 mg a day for migraines which actually works well to prevent them and I decided to add my other B vitamins. I take Solgar brand of B1 800 mg, Integrative brand of B2 400 mg, Pure brand for P5P50 for Vit B6 and Pure brand for B12 with Folate. I also take Pure brand for B5 Pantethine. I take Thorne Vit C 500 mg ascorbic acid with citrus bioflavonoids 75 mg. I was taking Vit D3 for years until my levels got up in the 80s so I've been randomly taking it now. It was also interacting with taking magnesium supplement of (Milk of Magnesia 30 ml nightly) in causing calcium deposits in my aorta. I also add about 2 to 3 grams of sodium a day and about 1,000 mg of Potassium in food form for both. My allergies have gotten a lot worse and my joint pain. In 2019 I got diagnosed with Stage 1 and 2 breast cancer hormone receptor type (the good type) and had a lumpectomy to remove it. I was unable to do radiation due to having a pace maker and had terrible side effects from anastrozole and tamoxifen. I got severe myalgia which led to severe tendon pain in my hands and now have joint pain in my hands. I have not taken any since Dec 2020 and still have pain. I have severe fatigue too. I wish B1 would have been a miracle drug but it hasn't seemed to do anything for me or if it has maybe I would have been worse than I am now. Would like to see a real large study done on this topic to see if it can really help people or not.

After taking a supplement called Parasym Plus my life changed drastically for the better, I felt as if I was in a fog for 6 years and it was very scary, almost immediately after taking it I felt as if the fog had lifted, I could think more clearly, got my sense of direction back and was able to drive again, I had the energy sit up threw an entire movie with I couldn't do for years, it also helped tremendously with chronic edema in my legs!

I'm still curious to take it; I read one fibro study that some only react with doses of 1800mg and not under this mark. so maybe I try a higher dose if nothing changes next few weeks

Run out of LDN I always got in India this year, and was worried of losing its benefit of reduction in sleeptime need (>10 hrs). Didn't happen since being on high dose thiamine.

1200 mg is my ideal dose for energy but insomnia became a serious problem. So I am taking 900 mg which improved the insomnia immediately but the energy decreased substantially (although it is still better than baseline)

Reduced edema dramatically along with heart muscle pain

My initial presentation of EDS & co. Was ITH and pericarditis after getting sick with a virus at university. (Coxsackie Virus B1, mycoplasma pneumonia and Chlamydia pneumonia. Also tested positive for babesia). Doctors prescribe huge doses of Diamox due to my intracranial pressure to no avail. I spent years trying to find 'natural carbonic anhydrase inhibitors' to replace or use as an adjunct to diamox. One day at work (working as drug and alcohol community and detox worker / prescriber) I

found a study regarding thiamine and diamox being used together for schizophrenia patients due to thiamine being a CAI - used in equal amounts to diamox i.e instead of prescribing 500mg of Diamox for example. Using 1 tablet of 250mg diamox and 1 250mg thiamine (or more) works as a great adjunct therapy, comparable and statistically relevant. And therefor reduces the side effects / amount used, of Diamox. I've recently started taking it again - this week. After a long health journey too long to explain. But.. I believe the CAI action, as well as the affect on the vagus nerve - thiamine can really help - us all.

It worked best when taken with my other vitamins C D3 B-complex coq10 nad+ etc
Took for neuropathic pain

It seems to actually be improving my sleep, I take it throughout the day, last dose 4 pm. I haven't been taking it very long, but imagine that other symptoms like fatigue and pain will improve if sleep continues to be better.

Strangely I didn't know I was taking so much til I read this article. I have since broken it up and split the dose between three doses. I was taking a two-capsule multi and a one dose B-complex. For years I had slept til 11am or later. When I started this vitamin regimen I started getting up at 8:30 am and didn't know why. Now that I am splitting the dose carefully I don't get the headaches after dosing. Also my AHI(sleep apnea) has dropped to a 1.5 or lower.

After having severe fatigue for 28 years I am getting some help with this. Not sure if it is relevant but I seem to react badly to B6.

I would like to combine it with vit B12 injections, which I did well with back in the 1990s but can't find doctor willing to prescribe them now in 2021. Glad the B 1 is over the counter or I would be prevented from obtaining a product that is helping me.

After a decade deteriorating, accelerated by covid mildly 12m ago, I seem to have stabilised and the thiamine coincided with an improvement in brain fog.

tried 1000mg initially, backed off to 500 mg due to trouble falling asleep

It has helped my head pressure and daily dull headache....also my weak muscles in my calves feel stronger. The head pressure change is most welcomed!

I was bedridden and have regained 75% of normal functioning with thiamine

I've found it very important to also take all the other b vitamins and essential minerals like magnesium while taking high dose thiamine. My improvements have only come while taking everything together.

My miracle is allthiamine- began 3/2020 and then in the month of August 2020 my high heart rate POTS went down significantly. I had been tracking it for many years on my SweetBeatHRV app. But thought I was NEVER going to find/advocate for myself the answers. I just never gave up searching and wow am I so happy.

The fatigue is still constant but the brain/Neuro inflammation is improved significantly.
I hope in the next few years to find myself back to work or volunteering,
Thank you for listening,

i get the same benefit from 300 as 500 mg so will be reducing dose in the future
I would like to try it again. This time I will titrate slowly over months and see whether it helps. I read that thiamin helps with insulin sensitivity which may have helped me as I am diabetic.

I started low dose naltrexone @ 4mg per night, 1 month after the high dose thiamine treatment started incrementally and I believe this has contributed to my cognitive and neurological improvements. I experienced no real symptoms from the thiamine, but severe symptoms about 5 days into LDN which lasted @10 days. After that I had greatly reduced symptoms.
tachycardia was a problem before, during, and after - probably not impacted too much by thiamine
I took it with my morning pills and vitamins. An hour later, I felt a slight boost that helped me get started on daily chores/work/activities. Getting started can be a real challenge.
I will continue to experiment with it.
currently recovering from Lyme and SIBO from long haul antibiotics. thiamine seems to have increased levels of stomach acid.

Really just starting

Thiamine took me from bedridden to upright and fairly functional within just a few weeks. It was truly miraculous. I took 600mg for a long while. It is important to try and balance other b vitamins along with potassium. Over time, thiamine has been less of a cure-all but is one of the most helpful things I've ever used. Please note many find TTFD the most helpful form. Shame your survey doesn't include it.

TAKE IN A.M.

I was given the dosage bc i presented with extreme lethargy and inability to continue workouts. I carry pdh deficiency. My son physically has it. They assumed that was my problem so they started me on 100mg x day then bumped it to 200mg x day. This helped for about a year. Then everything started slowly going down hill for the next 3 years. Food allergies were first, then carb intolerance (started modified keto,) energy started depleting, exercise intolerance, weight gain, leg swelling, muscle cramping, excessive thirst, constant electrolyte imbalances and beyond horrible night sweating all of which would get worse the closer to my period I got.

My ME sort of let go completely, after 2-3 days

GI tract feels better (less diarrhea/pain). Less 'Å%hlers Danlos pain'

Muscle tenderness in quads and muscle pain that ran along each side of my body (imagine doing a side stretch) completely resolved
Brain fog and fatigue near completely resolved I have increased to 1500 mg per day in last 2 weeks
I have been taking it with molybdenum, magnesium and other B vitamins so It's difficult to figure out what specifically the B1 does
The symptoms I have noticed could also be from having cfs.

B1 have been a life changer for ME. I have get some life back

This has substantially improved my quality of life.

Thank you so much for bringing this info out! It has helped me and several others in the norwegian Facebook group "ME - en vei ut" (ME - a way out). Personally I feel the explanation of blocked thiamine transport compensated by diffusion seems more likely than intracranial hypo- or hypertension since I never had severe headache and vision disturbances, and I can virtually feel energy "pouring in" on day 2-3 after starting thiamine again. It may also fit nicely into Fluge and Mella's findings that something in the blood of ME patients block carbohydrate metabolism and cause high lactate.

Started on 750mg Thiamin HCL (Iherb) then started on Thiamax 100mg and increased to 200mg as I take today. Brainfog got better with Thiamax and I feel that Thiamax in general works better for me. But both was a significant improvement from not taking any B1. Taking Thiamin has given me the Energy to be a part of my family and life in general, something I havent been able to in several years due to ME. Have been mostly housebound last 3-4 years.

Must have a break for a couple of days if I have taken too high dose. Then experiment for a long time to find stable dose. Still experimenting.

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It worked really well for while but now I'm back to my baseline from before I started taking it. With no change in medications/dosages.

I took all the vitamins B's (strong) and ekstra 300 mg Thiamine and went glutenfree! Benfotiamine, in combination with Ritalin, D-ribose, CoQ10, fish oil and low dose Naltrexone, has apparently cured my ME/CFS. I would no longer be diagnosed with CFS as I am free of most of my symptoms. I still have headaches sometimes and some orthostatic intolerance but I am able to exercise and hope this will improve. I'm looking forward to starting University and getting on with normal life

I get Crohn's flare and went to keto to try to fix the issue, but get a huge anemia it was hard to walk on stairs even one floor, and I had hypoglycemia (avg glucose of 60), it's all went away by only couple of days taking B1

200mg worked like magic for my IBD fatigue and helped my POTS. I was able to go for a walk for the first time in a year, and hikes too! But I was not liking having to get up to pee multiple times a night so I went down in the dose thinking maybe it was too much. I did this for 3 days but kept hiking which resulted in a terrible MCAS/pots episode I am still experiencing weeks later. I went back to 200mg but have no energy. Think my body still recovering from the episode. Not sure if I should stop the thiamine or continue. I wish I had just kept where I was :(

I have noticed that when I don't take it, I feel awful - I wasn't sure if it was doing much because I still have severe fatigue - however, my mood and energy drastically dropped when I experimented going off it.

The muscle pain goes away when I drink dandelion root tea.

Completely eliminated POTS in 1 week, ~50 bpm jump prone-to-upright reduced to ~15. Had measurable POTS for over a year, so coincidental improvement seems unlikely.

I take the same dose of Riboflavin with Thiamine HCL otherwise my BP increases. I also take magnesium and eat lots of potassium. HCL helps with vertigo, neuropathy and brain fog

Easier to breathe. Better memory. Easier to swallow. Reduced rigidity. I had fluids in my lungs that I no longer have.

Realized after taking it for a while my brain fog was worse and like I was operating with water on the brain. Increased dose to 1,000mg for one day and this got much worse so I stopped taking it. I think this was a gradual development up until this point

You need mast cell stabilisers, antihistamines, magnesium, potassium, riboflavin, NMN, pantethine, methylcobalamin, calcium, and phosphates for it to actually start working without a lot of side effects I have noticed.

I have chronic Hashimoto's, dysautonomia, and oral allergy syndrome following childhood EBV. I was under evaluation for POTS when I discovered Dr. Lonsdale's work, and my doctor supported a trial of high-dose thiamine. The thiamine seems to have completely reversed my POTS and allergy symptoms with no noticeable side effects.

i feel better if i also take Mg and K, as well as B Vitamins

My skin is beautiful, it is tightening up. My digestion is so much better. Many good things

My research reading medical studies pointed me to a different form of thiamine (Sulbutiamine) originally used by the Japanese to correct thiamine deficiency starting 50 years ago. From studies specifically to see which form(s) of thiamine could pass through the blood-brain barrier. Only one type could - Sulbutiamine.

Since myalgic encephalomyelitis literally means brain inflammation, I always look for supplements that reduce inflammation. They do help my joints, but none have made such a large positive change for my brain and its functioning as Sulbutiamine has. It's gratifying to do research, find something, and get the results I was after. None of the other things I have found do much, if anything.

My husband has been having varying degrees of focal awareness seizures resulting in tonic clonics and cluster episodes. No evidence of anything on brain scan. Was diagnosed with malnutrition as a child and told to take minadex but didn't, limited food intake and fits started after drinking alcohol. His anxiety has been bad but after the episode he starts on multivitamin eats well then when feels better slowly stops..... Discovered these articles. He has elevated bilirubin permanently as have our two daughters which we previously believed was Gilbert's. Suspect maybe genetic beri beri as his mum

has a b complex deficiency and similar episodes? Completed survey with husband permission. Soon as I could get some food and vitamins in this time he perked up and memory improved. His eyesight had got worse and after reading the data I asked him if it ever gets better and he said some days it's worse.

I used Allithiamin to fix sleep apnea where I would dream I had stopped breathing. I could feel I had stopped breathing and I would wake up gasping. This sleep apnea seemed to originate from my diaphragm. I would have diaphragm flutters as I was falling asleep. Diaphragm flutters were almost a guarantee of a sleep apnea episode that night. Taking too many polyphenols or too much black tea will throw me back into sleep apnea. I live in Arizona and it's really hot during the summer, if I work outside I will also get thrown back into sleep apnea. When it's really hot out I have to take even more thiamin. I think I'm going to be on high dose Thiamin for the rest of my life. I think I may have had many other symptoms of thiamine deficiency but it's hard to tell because I also had oxalate poisoning at the same time because I was eating a ketogenic diet. I was eating way too much spinach, black beans, black tea, almond butter and chocolate.

I am eternally grateful I have found this

Do you wish to share any other information?

My M.E. was very severe.

I worked my way through all the B vitamins, I always do better on the coenzymated versions, B1, B3, B5, B6, B9, B12 I did very well on these, (methylcobalamin & adenosylcobalamin were the two B12's that worked well for me), also TMG is a big win as well, all these things seem related, also I had a significant magnesium deficiency as well.

I had been taking Benfotiamine for several years but switched to thiamine after finding out about the blood/brain issue. I took 100mg and the next day had no muscle pain after work but I had also been on amino acid caps for 4 days at that time. It took me a month or so to start the 300mg dose of B1 & B2. I never mention PEM again and the fatigue was better but I was still dealing with Lyme/ mold/? It took about 6 months to build my strength back up and do enough strenuous work to conclude the CFS was gone. I also found out taking Vit B6 was bad for me. I have some detox pathways not right per some genetic testing but not MTHFR.

I would like to know where I can get accurately formulated and measured doses of thiamine instead of taking my chances with OTC supplements.

I crashed into CFS after taking metronizadole, a known thiamine agonist. Learned this from Derek Lonsdale, years after the event.

I found increasing my electrolytes to be the most helpful since I can no longer take Mestion. Haven't noticed much difference with my vitamin intake except taking my Bs helps prevent mouth sores that I get from not getting enough from having Celiac. Supplementing my Bs helps get rid of that and also works to prevent my migraines.

I believe more Dr's should know about this as I found out with my own research and it has changed my life drastically for the better, very exciting!

thank for this survey;

I have also recently discovered that Molybdenum also really helps. Just in case there is a link for your research.

I am also taking magnesium, Coq-10 , vit D , B12, started them 3 months before thiamine just started fludrocortisone, so far has increased fatigue

I have just discovered the information about using high dose Thiamine for intracranial hypertension, dull headache, Neuropathy and muscle weakness.... I have chronic Lyme, CVID and severe small fiber Neuropathy so I'm hopeful that thiamine can provide some symptom relief!

Initially High dose thiamine treatment is difficult to navigate particularly when you have brain fog. Most people would find it too difficult to understand without help from Dr Lonsdales book.

Thank you for this survey! Just wow! I am able to think again with allithiamine, xox

my CF/FM is very well managed overall with the use of various supplements - Ubiquinol, NAC, lowdose naltrexone - i have a demanding full time senior Academic position and can swim 1500 m 3 time a week - the B1 has improved my stamina and my already very mild post exercise fatigue - i plan to lower the dose from 500 to 300 mgs as this seems quite effective. I weigh 56 kilos.

Would like to know if there is any alternative to thiamin which will work at normal doses. I am scared of taking high dose of thiamin due to long term side effects possible.

I believe the introduction of LDN, with high dose Allithiamine has been key to my significant improvements over the last 2 months. My doc and I are still in the early stages of diagnosis/treatment and adjusting doses/diet to try and lower the widespread high percentage neuroinflammation and associated symptoms , but it seems we are on the right track unless I am just in a remission phase. I am advised to stay with 450mg per day of Thiamine for another 3 months and reassess. Time will tell.

I have had more energy, can read again even three days after stopping. Encouraging.

Thiamine dosage helped my joint and bone pain

I also take other mitochondrial food

I'd be very careful of the Derrick Lonsdale, Hormones Matter, Elliott Overton crowd. I find their advice dangerous, particularly with TTFD/allithiamine which can cause irreversible neuropathy. It's important to look at B1 in context and not as a drug. It works in multiple pathways, all of which need cofactors. I've had cfs for 30 years. The past 10 years have seen improvement. January 1, 2020, I had a terrible relapse. I spent the next 4.5 months on my bed. I am a little better but would be thrilled if Thiamine could help me. Thank you.

Im also trying sulbutiamine

None

LDN is helping a lot on the cognitive problems I had.

Gluten- and casein-free helped me A LOT, together with all vitamins and minerals (easily absorbable). Had to take antihistamines to tolerate probiotics 50 billion CFU.

I had Fibromyalgia (and migraines), ME/PEM, POTS, HIT and MCAS for 20-30y's

Lyme was the problem = Multi-infections (viruses and tick-borne bacterial, parasites and fungus). I'm still in treatment, getting better for every day. So important to get the immune system up again and take probiotics

I have also noted an improvement with high does biotin - I'm not sure what the mechanism of action (Sulfur component, repairing digestive tract, replenishing high turnover cells... lots of speculative research)

I believe that high dose thiamine saved my life. I was that much ill I was dying. I am still alive after 2 years

I encourage you to look into Sulbutiamine. I am taking the Health Naturals brand. I don't know much about the different brands of it.

I think my mother might have died along slow death of thiamine deficiency and I believe I also saw signs of thiamine deficiency on my children