Frequently Asked Questions about
High-Dose Thiamine (HDT) Therapy

Responses by Dr. Antonio Costantini
and Marco Colangeli, his Research Assistant since 2011

General Information for the Patient

Dr. Costantini and His Work

- ***Who is Dr. Antonio Costantini?*** *(used with permission)*
- ***Radio interview with Dr. Costantini and Marco Colangeli*** *[in Italian]*
- ***PD symptoms before and during HDT Therapy***
  [Dr. Costantini's YouTube channel – patient videos used with permission]
- ***Video interviews of some of Dr. Costantini's Italian patients*** *describing their experiences with HDT [currently in Italian only]*

Frequently-Asked Questions about HDT Therapy

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53. Is it possible that I could control my PD symptoms with thiamine alone, and not need PD medications or other supplements?

54. If I am using Mucuna pruriens (aka Mucuna or MP), can I benefit from taking thiamine at the same time?

55. Have you ever seen thiamine cause back and leg pain, and muscle tension?

General Information for the Patient

Video interviews of some of Dr. Costantini's Italian patients describing their experiences with HDT [in Italian]

Frequently Asked Questions about HDT Therapy

1. What is the standard starting dose of thiamine?

A "standard dose" of thiamine in our protocol does not exist. The dose that we have been using more frequently in PWP is 4g/day orally (tablets) or 2 injections of thiamine IM of 100mg each, twice a week.

However the right dose is always tailored to the specific characteristics of the patient: weight, duration of the disease, severity of the symptoms.

2. Does the dose stay the same or does it have to be adjusted up or down over time?

Initially it is possible that the dose is to be adjusted based on the patient's response to the treatment. Once the right dose has been found, such dosage should not be changed and it should be always effective.

The "right dose" is found when the disturbed balance is suppressed and the patient regains normal balance. In other words, the right dose is the one which normalizes the pull-test.

On the basis of our observations, the right dose is the one which suppresses the majority of the non-motor symptoms and at least 50% of the motor symptoms.

The right dose does not cause "overdosage symptoms" (see further questions for more information on this point).

3. What does it mean if I become jittery after starting thiamine, even at a lower dose?

On the basis of our experience, if symptoms like jittery appear at the beginning of the treatment, this may mean that such dose of thiamine is already too high for the needs of the specific patient.

4. Is thiamine compatible with all PD-related drugs?

Thiamine can be administrated in association with any of the existing therapies for PD as well as it is compatible with any other drug on the market.

The intramuscular injections (usually the 100 mg phials shots) must be performed by qualified personnel in order to avoid bruises in patients using anticoagulant drugs such as Coumadin, Sintrom and similar.

5. What is a realistic time line before symptom relief is seen?

The oral therapy produces an appreciable improvement within a few days, but sometimes the patient may not realize it. This is the reason why we always request and perform a video recording of the patient before and after the therapy, at regular intervals, to be used as reference.

Within 30 days in most of the cases, a clear and appreciable improvement of the symptoms is detected by the patient as well. A further improvement is observed within the following two-three months.

There exist an oral dose (OD) and an intramuscular dose (ID) that differ in absolute quantity but which are equal in effectiveness. However, if the intestinal absorption is not optimal, the OD may require to be increased to counterbalance for this condition, or to a certain level the patient may need to be switched to intramuscular regime and have the optimal ID.

The effectiveness of one intramuscular injection (100 mg) is nothing short of impressive in all cases we observed. One phial determines an almost sudden improvement that is clearly appreciable by the doctor as well as by the patient.

This improvement concerns primarily the facial mimic and expressions, the muscular tone, the mood of the patient and his/her movements and speed, and the reduction of the tremor. Within one hour the UPDRS improves by some 30-40%.

The improvement is clearly visible by the videos recordings before and after the shot. In all of our patients we carry out the UPDRS and the recordings. The patient is asked to speak and his/her face is recorded, is asked to walk, write, and perform other activities. In addition we always carry out the pull test.

Subsequently, the patient, as in the case of the OD, will continue improving for the following two months or so, reaching a stable clinical condition.

6. Do tremors eventually go away over time?

The tremor is highly reduced, though being one of the sturdiest symptoms of PD, usually it is indispensable that l-dopa is also administrated to the patient.

It is rare that a patient who follows our protocol does not experience an appreciable or often even nearly complete regression of the tremor.

7. What other vitamins or supplements should I take to optimize the benefit from thiamine such as magnesium, other B vitamins or vitamin D?

In our experience, we do not add multivitamin compounds to the treatment with high dose thiamine. Thiamine HCL usually is effective against the symptoms of PD (as well as the other diseases we have studied) alone.

In the case in which the response of some patients requires a further enhancement of the therapy, we may add low doses of other group-B vitamins and magnesium.

It should be noted that vitamin B6 facilitates the action of peripheral dopamine-decarboxylase. Since Madopar and Sinemet contain strong inhibitors of the peripheral decarboxylase, it is rare that vitamin B6 produces negative effects. However, even if rarely, it may happen that high doses of vitamin B6 may reduce the quantity of l-dopa which enters the brain and create a worsening of the symptoms within a few days.

8. Is thiamine ever contraindicated with other health issues that a person might have simultaneously with PD?

In literature thiamine is not contraindicated in any disease, and actually in many cases is deemed useful in a number of diseases such as diabetes in addition to other drugs.

9. If I miss a dose or a day of thiamine, will my PD symptoms come right back?

No. If a patients misses one day or so of thiamine treatment there will not be any consequence.

Once the patient is stabilized, after three or six months, we usually suggest short breaks of one to two weeks without thiamine.

Some patients suspended the high dose thiamine treatment and the symptoms of the disease came back after two-three months; thus, these patients restarted the high dose thiamine therapy as before and, like before, the symptoms disappeared again.

10. Are there many things I should not take with thiamine such as alcohol?

Based on our experience, if consumed with moderation (i.e., 1 glass of wine a day), alcohol does not affect the condition of the patient treated with our protocol. In Italy at least, wine is a quality product which, again with moderation, is not detrimental to the

health of the patients. I suggest that spirits and liquors and large quantities of alcohol are not consumed by PD patients. In general, a healthy lifestyle is suggested and should be maintained by any patient.

11. Are there known side effects associated with the use of high-dose oral thiamine?

The only known side effects associated with the therapy we devised are linked with over-dosage: when the dose of thiamine is higher than the needs of the patient, then there is a worsening of the symptoms of the disease. This, as stated above, flags the need to adjust (usually reduce) the dose of thiamine.

12. Is it better to take thiamine on an empty stomach or with food?

Some of our patients reported to us that they have better effects if taken on an empty stomach, however as far as we are concerned, thiamine is effective also after a meal.

13. What happens if I take my thiamine later in the afternoon or at night?

If high oral doses of thiamine are taken later during the day (evening or night) there may be difficulties in falling asleep. Conversely, if taken in the morning and early afternoon, patients reported an improvement of their sleep.

14. Do PD symptoms continue to improve further after 6 months of everyday use?

Based on our observations, patients reach the peak of the improvement within 3-6 months and no further improvement was observed past that.

15. Are there some PD symptoms that thiamine does not seem to help with?

Thiamine is highly effective with all symptoms, both motor and non-motor ones.

16. Will thiamine work for all motor and non-motor PD symptoms?

Thiamine is effective against both motor and non-motor symptoms. In PD the non-motor symptoms are less pronounced than motor ones.

Almost always, the high-dose thiamine treatment (thiamine alone, without other drugs) is capable of suppressing or quasi-suppressing symptoms like depression, fatigue, and cognitive impairments.

Often the bowel movements improve; so does the sexual potency and the sense of smell.

Motor symptoms are tougher to eliminate and do require the addition of adequate doses of l-dopa which are made incredibly more effective by the high-dose thiamine protocol though. The protocol we devised, in fact, always requires the addition of l-dopa in order to suppress the motor symptoms.

Out of 2,500 PWP, we have five patients with very recent emergence of PD who are treated only with high-dose thiamine and they do not present any symptom of the disease.

We observed that Thiamine also favors the regression of dermatitis and rehydrates the skin.

17. Does thiamine work for other health issues?

We have treated and published peer-reviewed articles about the following health issues in which thiamine is effective like in the case of PD:

- fatigue in inflammatory bowel diseases,
- post-stroke fatigue,
- fatigue in multiple sclerosis,
- fatigue in thyroiditis disease,
- fibromyalgia,
- spinocerebellar ataxias,
- Friedreich ataxia,
- Steinert disease (muscular dystrophy),
- dystonia,
- essential tremor,
- cluster headache, and
- migraine.

Studies on further health issues and specifically neurodegenerative diseases are currently under development. Stay tuned.

18. What are the symptoms if my thiamine dose is too high or too low?

If the dose is too high, rarely but sometimes it has happened, can determine the worsening of the symptoms of PD. Sometimes after an initial improvement, if the dose is too high, some symptoms that had disappeared may manifest again.

The therapy with high-dose thiamine has to lead only to positive effects, if any negative effect is observed by the patient this means that the dose is to be adjusted.

A dose that is too low does not lead to any beneficial effect on the symptoms of PD.

19. Will thiamine have any effect on my "ON" times and "OFF" times"?

The treatment with high-dose thiamine that we have devised increases the duration of the "ON" times and reduces the "OFF" times.

It also reduces drastically hyperkinesia and dyskinesia.

20. Does thiamine have any effect on sleep?

Our patients reported that the high dose thiamine therapy has beneficial effects on their sleep.

21 Is it possible to get a rash from taking oral thiamine?

Yes, very rarely it may happen.

22. What effects can thiamine have on mood?

Usually, thiamine (employed alone and without the addition of antidepressant drugs) can improve the mood of the patient in a satisfactory manner.

23. Are there times when I should reduce or increase my dosage such as under highly stressful conditions?

In general, there is no need to vary the dosage once the right dose has been found and confirmed.

24. Is it better to start at a low dose and slowly increase the dose each week, or is it better to just go to a full dose right at the start of thiamine therapy?

It can be done in both ways. If the practitioner is experienced enough and has the chance to follow closely the patient (like we do with our patients) the treatment can start immediately with a dose assumed to be "right;" other times it is best to start increasing gradually until the symptoms improve satisfactorily.

Clearly, without an in-person checkup it is difficult to guess right away the correct amount for the patient and some adjustments may be necessary.

25. Can a person have such severe PD that thiamine will no longer be of benefit for symptom relief?

In our clinical experience all patients responded favorably to the therapy regardless of the severity. Clearly, the results of the therapy depends upon a number of factors, including the amount of neurons that can still be brought back to life by the treatment.

26. If I get a cold or flu, should I continue taking the thiamine?

Yes

27. How many PD patients have you treated with thiamine?

Certainly more than 2,500 in Italy alone. Currently we are assisting a number of PWP remotely with encouraging results.

The results are impressive and they last over time. Many of our patients are following our protocol now for 5, 4, or 3 years and are in rather excellent conditions considering the place they started from. The progression of the disease has been halted.

Given the efficacy of the treatment and the lack of support from the scientific community, many patients overseas apply a DIY approach which we do not recommend but can understand.

Those patients have the right to claim that their neurologists open their eyes to the possibilities offered by this therapy and try it themselves to embrace its potential.

How many more patients could be helped if their doctors would put aside their skepticism and egos and humbly open up to try and learn more about the use of high-dose thiamine?

28. Are there people who cannot tolerate thiamine treatment?

We had 1 patient out of more than 2,500 who experienced vomit every time she assumed thiamine in high doses and thus the therapy did not apply to her.

29. Does thiamine help with depression and/or anxiety?

Normally the high-dose thiamine treatment improves depression and anxiety considerably.

30. Does thiamine alleviate Lewy Body Dementia and all forms of PD?

We have some encouraging data but it is too early for us to express an opinion on this aspect.

The most encouraging of those results were detected in the corticobasal degeneration (CBD). The doses employed are much higher than those used in the treatment of PD.

31. Can thiamine help a PWP with pain symptoms?

A patient from the UK, male 99.5 kg, experienced as principal symptom a "terrible pain," in the words of his wife who contacted Dr. Costantini in late May.

After the initial discussion and first few days of treatment she reported that her husband was completely pain-free.

Many other of our patients affected by relevant pain, informed us that this disturb regressed completely or nearly completely already within a few days (oral therapy) or within a few hours (intramuscular shots).

32. Do people taking Levodopa and following Thiamine protocol develop Dyskinesia?

[Marco Colangeli:] I have consulted with Dr Costantini about your query and I do confirm that on the basis of our observations, our patients who do use l-dopa in addition to thiamine have not developed dyskinesia. This is true for patients who are under treatment for 3 to 5 years (we invented this treatment in 2013). However, you should inform Dr Costantini or myself about your current l-dopa regime and he will see if it needs to be adjusted.

We do consider the timeframe above "long term" but further studies are necessary to confirm that patients will be dyskinesia-free lifelong, though we are optimistic.

We observed that the right dose of thiamine can lead to an improvement of the symptoms between 50 and 80-90%, but in order to push towards the complete regression of the symptoms, the correct dose of l-dopa should be coupled to power the dopaminergic motor circuits. L-dopa then shall no longer lead to DYSKINESIA if used together with the high-dose thiamine.

The treatment is based upon the hypothesis that the disease leads to the death of neurons through its interaction with the intracellular metabolism of thiamine. This action can be blocked by the administration of high doses of thiamine. The neurons, once no longer burdened by the primary cause of the disease, restart their activity and this leads to the improvement of most symptoms.

Continuing the therapy, the neurons might stay healthy regardless of the existence of PD. Thus, in addition to a rapid improvement of the symptoms we observe also a freezing of the evolution of the disease.

However, the primary cause of the disease is not directly interested by the therapy. High-dose thiamine does not eliminate the primary cause of the disease but blocks all damages inflicted by the disease. Therefore, the high-dose thiamine is a pathogenetic therapy. The therapy thus limits the degeneration of the nervous system which continues to work efficiently when freed from the limitations posed by the disease.

When the high-dose thiamine is suspended after a cycle of treatments of three months, the beneficial effects do not cease right away but start to diminish within the next two months. We believe that this happens because the mechanisms of action of the disease have a certain buffer effect which in turn requires a couple of months before getting back to the status of the symptoms before the use of high-dose thiamine.

33. If I need to stop taking other supplements to start thiamine therapy, when can I start to add them back?

Q: It seems that your preference is for most people to stop use of all supplements in order to start thiamine therapy and I assume this is so that you can have the clearest picture of exactly how these patients are responding to the thiamine therapy itself and in turn this helps you to determine if dose adjustments are needed? You are also trying to make sure that the other supplements are not clouding the effect of thiamine therapy?

If this is correct, at what point can a patient start to add back supplements they were already taking as part of their daily regimen?

A: That is correct. We usually prefer to have a glimpse of how the high dose thiamine performs alone before evaluating the need for further supplements to aid its absorption (e.g., magnesium, etc.).

Usually, after 3 months from the beginning of the therapy, we reach the point where the thiamine protocol has been correctly tailored to the needs of the patients and in case the regression of the symptoms still leaves room for improvement, we add other supplements and observe possible changes for further 3 months.

Often times the action of thiamine alone is satisfactory for the patients and rarely we need to add other supplements, which are in any case in small doses.

34. Will catching up on a missed dose before the next dose is due keep a steady state of thiamine in my system?

Q: If thiamine usage late in the day does not keep me awake at night, is it okay to take it before dinner if I miss my lunchtime dose? Will taking the second dose before dinner help to keep a steady state of thiamine in my system?

A: If the use of thiamine does not lead to difficulties in falling asleep or sleepless night there is no reason why a patient should not take before dinner.

As for the stability of dose in the system we cannot express an educated opinion since the testing of thiamine levels in the blood is an uncommon test and perform it at different times of the day would require (once again...) a dedicated study which we have not been able to carry out with our resources to date.

35. What is the "pull test" you talk about? Is there a video I can watch that shows how to do it?

You mention the "pull test" on occasion, can you you explain this in detail or link to a video that describes this procedure?

A: The PULL TEST is a common component of the UPDRS scale for PD. At this link (https://www.sralab.org/rehabilitation-measures/retropulsive-pull-test) you can find an explanation of what that is and how it should be performed and evaluated by the neurologist. Instructions below explain how to do it at home and about the score.

How to Do the "Pull Test":

1) Subject stands in a comfortable stance with eyes open (have feet shoulder width apart, if at first the subject takes an unusually wide or narrow stance).
2) Examiner stands behind the subject.
3) The subject is instructed to do whatever it takes to not fall and are told that the examiner will catch them if they do fall. (Examiner must be ready and able to catch the subject in case of falling.)
4) The examiner gives a sudden, brief backward pull to the shoulders of the subject with sufficient force to cause the subject to have to regain their balance.

5) The subject should not know exactly when the pull is coming.

Pull Test Score from 0 to 4:

0 = recovers independently may take 1 or 2 steps or an ankle reaction

1 = three steps or more backward but recovers independently

2 = retropulsion, needs to be assisted to prevent fall

3 = very unstable, tends to lose balance spontaneously

4 = unable to stand without assistance (UPDRS method)

Here is a video of Dr. Costantini performing the pull test on a patient (see link below). He stands behind the patient and gives a firm pull or tug at the front of the shoulders so that they are quickly pulled backwards.

This puts the patient off balance and he is checking to see how quickly the patient regains their balance. Specifically he wants to see if you can regain your balance without having to take a step backward or only one step backwards.

If it takes more than one step or you fall, then balance is not optimal and he may adjust the thiamine dose based on this test.

Dr. Costantini performing pull test: https://www.youtube.com/watch?v=IPxxkCZJbyo

See the link below to take the UPDRS test online:

UPDRS
1) Go to http://farmacologiaclinica.info/scales/UPDRS-PARKINSON/
2) Click on START SCORING
3) Take the UNIFIED PARKINSON'S DISEASE RATING SCALE test online or with your mobile phone or tablet.

36. Do you have an interest in patients who have a DAT scan for later comparison?

Yes. The DAT scans are a useful system to compare the progression of the disease and the possible actions of the high dose thiamine therapy.

Especially if the patients have recent DAT scans and will be willing to compare the results with a future scan performed in 5 years (this seems to be the minimum time window to make reliable considerations) from the beginning of the therapy, that would definitely be interesting.

37. Can thiamine cause hypertension in some people?

It could, and if that does happen the doctor should operate either on reducing the thiamine dosage or adjusting the anti-hypertension therapy of the patient.

38. What is the longest period of time that you have treated a PWP with thiamine?

Five and a half years.

39. if you take carbidopa-levodopa (as Sinemet) will the thiamine still prevent late stage-development of problems like dyskinesia?

Q: Some members on the HU [HealthUnlocked] forum are asking a question about your recent email about Levodopa and thiamine.

The members seem to agree that levodopa is not the problem, as you stated in your email, but they feel the problem is the carbidopa that is often included with their levodopa prescription as both in one capsule. I believe the product is called Sinemet that has the levodopa and carbidopa together.

The question then, if you take carbidopa/levodopa (as Sinemet) will the thiamine still prevent late stage development of problems like dyskinesia?

A: Certainly. Yes.

40. Does thiamine interact with warfarin?

Thiamine does not interfere with any oral anticoagulant. It must be taken by mouth and not by injection.

41. Can I use benfotiamine instead of thiamine hcl and still get the same results as thiamine hcl?

We don't use benfothiamine because previous trials report it does not enter in the neural cells, that's why it is not used for the diseases which don't affect the Central Nervous System (Bettendorff L.). We administer thiamine cloridrate intramuscularly or oral thiamine hcl effectively.

42 . How do you decide whether to prescribe injections vs. oral dosing (pills or capsules)?

Q: Forum member, Kia17, recently asked Dr. Costantini how he determines when he will prescribe intramuscular injections of thiamine or oral thiamine in pill or capsule form?

A : When we began to study the effects of thiamine on fatigue associated with inflammatory-autoimmune diseases, in Italy there were available in pharmacies only 300 mg tablets for the oral therapy and 100 mg phials, the latter to be administrated intramuscularly via shots.

Already starting from 2011 we realized that the phials therapy is 140 times more powerful than the respective oral dosage. In other words, in order to obtain the same clinical results of a patient taking 100 mg shots once a week, s/he should take orally 14 grams (100 mg x 140) of thiamine in tablets per week, thus over 7 days that means 6 or 7 pills (300 mg each). This was immediately felt as an issue both for the cost of the therapy as well as for the need to swallow a large number of pills each day, lifelong.

It should be noted that at that time I was little aware of the potentialities of the internet and the opportunities it can offer to consumers, and in this case to patients.

Therefore, back then, if in order to treat the fatigue a reasonable number of pills was necessary, we would stick to the oral therapy, whereas if the patient required 6+ tablets/day, we suggested to switch to an intramuscular therapy.

When we passed to the treatment of neurodegenerative diseases we learned that the necessary doses were on average even higher. The dose that we find more commonly used among our patients in Italy is 2 x 100 mg shots per week. The equivalent oral dose would be 13 x 300 mg tablets per day or 8 x 500 mg tablets per day depending upon the availability of the pills and the difficulties to swallow that some patients may or may not have. In most cases our patients prefer the intramuscular therapy.

After a few years of the intramuscular treatment however, the glutei begin to be affected by the treatment and it is necessary to switch, if even temporarily, to an oral intake regime. Most of our patients who have been treated with shots for a few years now with 2 shots per week have no issue to report.

The effect of intramuscular or oral thiamine is the same provided that the correct dosage is chosen, depending upon the different administration options, but the phials have a much more immediate action, the oral therapy is much slower and milder, possibly due to difficulties with the intestinal adsorption.

Clearly all patients who are under treatment with anticoagulants must do with the oral therapy, regardless of the number of pills they need.

In Italy this is how it works: the patient comes to the ambulatory and is examined. On the basis of the examination he receives a prescription to purchase the phials or the equivalent dosage in the form of tablets. A nurse performs the injections. However, sometimes the patient himself is capable or has someone to assist him/her (usually spouse or relative) who is capable of performing an intramuscular injection.

On the internet, both phials and tablets (up to 500 mg) are available even without a prescription.

It is worth it to point out that in the cases in which the patient cannot take care of the intramuscular injections alone and thus requires the support of a nurse or his regular practitioner, there have been often reluctance from other neurologists or MD to perform the injections as per our therapy. This is why, when I do not have the opportunity to examine the patient directly, and thus have to resort to email exchanges only, I tend to prefer the oral therapy for ease of use.

Based on my clinical experience then, one reason that made me prefer the oral therapy in some patient is also due to the observation (to be confirmed) that patients of Anglo-saxons origins (Northern Europe and the USA) and Africans require much smaller doses to reach the same clinical results of their Italian mates. This makes it easier to go for an oral therapy in these cases.

Currently, I have email exchanges with about 300 PwP and many required that doses were halved as compared to my initial estimate. This may also be due to the lack of proper assessment of the status of the patient, that is obviously much less accurate without an in-person examination of the patient.

43. Will your thiamine protocol be of any benefit for PwP who have delusions, illusions, and hallucinations?

Yes, very often, when they are not due to prescription medications, but are a direct effect of the disease.

Medication-related issues regress only with dose reduction or replacement of the offending medication.

44. Does it seem that thiamine can prevent or improve PD dementia?

Q: Does your experience with thiamine in your patients suggest that thiamine can prevent PD dementia from getting started in the first place or can it have a positive impact in a PWP who already has PD dementia?

A : Usually cognitive disorders in PD are mild or medium. These have good regression with thiamine that also prevents the appearance, but there are cases where the patient appears to have severe dementia and motor symptoms of

Parkinson's Disease. In that case we have no data, but the impression is that dementia is not very sensitive to treatment.

45. Is thiamine compatible with DBS (Deep Brain Stimulation)?

Q: Do you know if thiamine is compatible with DBS, and if it is, is the dosing the same or different ? Can DBS mask or hide a thiamine dose that is too high?

A : Thiamine is DBS compatible and cannot mask anything. Dose remains unchanged from non-DBS.

46. Can diuretic medications prevent thiamine from working?

Q: I recently watched a video that said that diuretics can block certain thiamine activity as it relates to the heart and I was wondering if that may apply to the brain to some extent also? Could it be a factor in how some people respond to thiamine treatment?

A : Diuretics can block some of the activity of thiamine, but I don't think they are a factor that interferes with the response to thiamine in Parkinson's.

47. Can thiamine help with peripheral neuropathy?

Q:I was wondering if thiamine has shown benefit for peripheral neuropathy related to PD and or not related to PD?

A : Unfortunately, we have never been able to observe and treat a case of PD with peripheral neuropathy.

However it is a classic approach to many neuropathies to use vitamin B-1, B-6 and B-12.

48. Should the "pull test" be performed during "ON" time or "OFF" time?

Q: I have another question regarding the "pull test". Should this test be performed during "off time" or during "on time"?

A : It is better to do this during "ON" time because during the "OFF" periods the test can sometimes not be carried out and can also be distorted by facts not strictly related to balance disturbances.

49. I'm afraid to try thiamine, because what if I get worse before the right dose is found and never get better again?

Q: [By Marco Colangeli] Recently it has come to my attention that there are some PWPs who basically are afraid to try thiamine because they have read of the ups and downs of symptoms that can come into play during the sometimes-frustrating period of trying to determine the correct dose of B-1 in each individual.

The fear is that if I get worse than I already am, what if I don't get better if I completely stop taking B-1!

This is a legitimate and important concern that needs to be addressed, so I wrote Dr. Costantini to ask about this important concern by PWPs who are seriously considering testing B-1 and the following is his answer.

A . We have never had a case that has worsened irreversibly. As you know, we treat about 4000 patients in total.

On the other hand, the rationality of the therapy already excludes it. How can a constituent element of our organism cause us permanent damage at the dosage we are using?

In the literature there are some cases treated for many years (with doses equivalent to those we use) that are carriers of a genetic mutation of genes that encode the transport proteins of thiamine inside the cells (thiamine transporters). Even in these cases, nothing suspicious has ever been reported and there is no possibility that high doses of thiamine could cause permanent damage of any kind.

50. If at any point my PD symptoms get worse instead of better, does this mean thiamine won't work for me?

Q: [By Marco Colangeli] Some people have reported that when starting thiamine they soon develop a worsening of symptoms and consequently stop B-1 because they think it doesn't work for them. I have seen people report this multiple times.

This is the problem with trying to go it alone as opposed to following Dr. Costantini's advice of staying in constant contact with him via email while testing B-1 [finding right dose]!

For this question I asked Dr. Costantini to address the issue of people who find their symptoms worsening early on in the B-1 testing [finding right dose] process, as this is a very critical time that can make or break the protocol for them and either result in leaving the protocol behind for good or continuing on to possibly great results, and fortunately, the answer is simple! Here it is.

A . The sooner the worsening appears, the lower the dose of thiamine that will be required to make the patient feel good!

51. After I am stable on the right dose of thiamine, will I ever need to increase my PD medications like Levodopa/Sinemet? Could I even decrease how much of them I take and still feel good?

Q: Once a person has established the correct dose of thiamine/B-1 and is stable including a very good Pull Test response and a very good symptom reduction, will that person ever need to increase their other PD medications such as Levodopa/ Sinemet? Is there any possibility that these standard medications might be reduced?

A. Once a person has established the correct dose of thiamine/B-1 and is stable, including a good response to the Pull Test and a good reduction of symptoms, this person will never need to increase their other PD medications such as Levodopa / Sinemet or other drugs. There is a possibility that these standard drugs may be reduced especially if they have side effects.

52. After I am stable on the right dose of thiamine, what happens if I suddenly stop taking it?

Q: Once a person has established the correct dose of thiamine / B-1 and is stable, including a good response to the Pull Test and a good reduction of symptoms, if this person suddenly suspends thiamine what happens?

A . Nothing appreciable happens. The patient's condition does not change for 1-3 months.

This is because the attack of the disease, not opposed by thiamine, starts again, but it takes a long time before it damages the cells again before they are healed by thiamine.

We have numerous confirmations in this regard, so much so that in Italy we used to suspend thiamine one week a month to avoid risks of overdose and give the impression of "freedom" to the patient.

Look at Alberto's video on *highdosethiamine.org* (Dr. Costantini's website): after two years of treatment, it was recorded with the patient who had not had thiamine injections for three months.

After this period the symptoms begin to reoccur; the same dose of thiamine begins again and in a short time everything returns as before the suspension.

53. Is it possible that I could control my PD symptoms with thiamine alone, and not need PD medications or other supplements?

Q: [By Marco Colangeli] Recently I asked Dr. Costantini if some PWPs can take B-1 by itself without prescription meds or other supplements because the question has come up multiple times on the forum. He sent his reply today and here it is.

Importantly, please keep in mind that there is a very broad range of symptoms in PD and to a similar extent, a very broad range of PWPs at various stages of disease progression and though you may feel your symptoms are severe, Dr Costantini, in his broad experience may not feel the same because he is taking into account the fact that there are some very advanced stages of PD that he has seen in over 3,000 patients on his B-1 protocol.

A: When the patient has been diagnosed by us for a few months with a mild symptomatology and without any therapy in place, or we diagnose him at a very early stage, we treat him only with thiamine and often with lower doses than patients who are at a more advanced stage. The patient improves considerably and remains at a standstill.

It is difficult, however, given the previous damage, that the symptoms, especially the motor ones, all have a total regression. The surviving cells, even if healed, are not able to do all the work that the system did when it was healthy.

At this point either the patient is content to have some slight symptoms or get the complete abolition by adding to the treatment small doses of levodopa.

We only have three patients who use only thiamine because they have had a complete regression of symptoms.

Furthermore, suppose that for any reason the patient cannot or does not want to take any kind of classical treatment for Parkinson's disease; the right dose of thiamine can give him, at any stage of the disease, an improvement that can range from 30 to 70%, while at the same time abolishing the progression of the disease!

[By Marco Colangeli: Apparently Dr. Costantini wants to be very clear on this subject because he has responded to it in 3 separate emails! This is his third addition on this subject :]

To be clearer: all Parkinsonian patients, at any stage of the disease have benefit on symptoms and stopping the progression of the disease, whether or not they are being treated with other drugs.

We do not have any patients who do not respond to treatment with thiamine.

54. If I am using Mucuna pruriens *(aka Mucuna or MP), can I benefit from taking thiamine at the same time?*

Q: There are several forum members who are using *Mucuna pruriens* (MP) as a non prescription substitute for levodopa and consequently there is curiosity about adding B-1 to a regimen that includes MP.

Clearly some members are already using this combination to good effect and it appears from their comments that, like levodopa which has shown synergy with the B-1 protocol, so does MP.

I asked Dr. Costantini to weigh in on this subject and the following is his answer.

A: Thiamine has the same beneficial effects regardless of what therapy the patient is using and is compatible with almost any type of medication, so any patient can do the treatment they want.

Unfortunately I don't know the results of the addition of *Mucuna pruriens* compared to carbidopa-levodopa.

55. Have you ever seen thiamine cause back and leg pain, and muscle tension?

Q: A forum member recently asked Dr. Costantini, " Have you ever seen any side effects in the form of back and leg pain and muscle tension?"

A. Yes, when the dose is slightly excessive compared to the needs of the patient.

General Information for the Patient

(Read carefully)

The dose of thiamine in the future can be increased or even decreased depending on the result obtained.

First of all you have to take a short videotape of your face while you speak, of your walk, and of the pull test made by a relative or friend. To determine the right dose in future we will follow this criteria.

First of all we need to say that, if the dose of thiamine used is excessive for that patient, it can determine, after an initial improvement, a worsening of his symptoms previously improved (rarely a worsening already at the first dose can happen).

In this case we invite the patient to suspend the treatment with thiamine for a week, the worsening regresses and then it can be restarted with halved or lower doses.

The right dose should not give the side effects of overdose, improve at least 50% of all the symptoms of the UPDRS scale, and bring the PULL TEST to normality (score 0).

The pull test reveals almost always a pathological balance, even in the early stages of the disease. As a rule, if the examinator behind the patient gives him a strong push towards the shoulders, he / she takes a few steps behind or falls down. This symptom is only improved by thiamine being non responder to other treatments.

The normalization of the patient's response tells us the dose of thiamine is the right one.

The normal subject['s response] to the pull test is [to stay] still or [the subject] almost takes a step backwards.

I hope the answers above are useful.

Thank you
Best regards

Marco Colangeli, research assistant for Dr. Antonio Costantini
https://healthunlocked.com/user/surfdivinity/activity

Who is Dr. Costantini?

Written [2016-2018?] by a HealthUnlocked member (user name 'cincinnato"). [https://healthunlocked.com/user/cincinnato] and originally posted to the HealthUnlocked group "The Parkinson's Movement," a forum for discussing and sharing information and support on all aspects of Parkinson's Disease [https://healthunlocked.com/parkinsonsmovement].

*[**Note**: Privacy policy at HealthUnlocked strongly recommends that members choose user names to protect personal health information they may share with other members in the course of using the HealthUnlocked site and services.]*

*[**Editor's note:** The piece below, originally written in Italian, was auto-translated to English via DeepL.com/Translator before the noted edits were added.]*

> ***Admin Update (8 Sept 2019):*** *Due to personal health issues, Dr. Costantini ceased to practice medicine in early 2019. He is no longer available for consultation, either in person or via email, and deeply regrets this unfortunately necessary change.*

He is a neurologist in Viterbo, Italy with his own practice and 2,700 + patients that he is treating with thiamine as an adjunctive treatment to their standard PD meds. He has been treating his patients with PD for over 5 years now during which time no apparent disease progression has been observed while symptom improvement has been significant for most patients.

As far as thiamine, he has been working with it since 2010/2011.

He said that even if they couldn't come to his clinic, he could still try to treat them via email. He said he needed a copy of their medical records and short videos of a Pull Test, of them talking, writing and a short video of them walking.

> **Note:** upload your videos to YouTube [edit: *use* ***Privacy setting UNLISTED***] and then share [edit: *the links*] with Dr. Costantini via email.

He said the videos were not for him, but rather for the patient to watch every now and again so they could have a basis for comparison as time passed.

- Dr. Costantini published his first study on Parkinson's [edit: *and thiamine*] in 2013.
- He later published two more with other co-authors such as Dr Roberto Fancellu working at the S Martino Hospital in Genoa (recently he was [edit: *nevertheless*] denied funding for a double-blind study).
- He has also published on other serious diseases.
- His studies have a total of 150 citations, and by great authors.
- No neurologist who is involved in the compilation of guidelines for the treatment of this disease, no renowned neurologist, all with a great culture on the subject, have bothered to deny [edit: *Dr. Costantini's results*], with data in hand. It [edit: *High-Dose Thiamine therapy*] is simply ignored.

Even in Italy, no one takes care [edit: *notice*] of it except for a few.

I, for what I could touch with my hand, no one replies against him because he already knows that he would fight for a cause lost at the beginning.
[edit: idiomatic translation = *With my hand on my heart, I believe nobody speaks to refute Dr. Costantini's assertions because such a speaker already knows that such an attempt would be a lost cause.* ??]

In Italy, Dr Costantini treats about 4000 patients. Everyone, without distinction, asks him this question, in the face of the wonderful prospects that the treatment opens up: how come all the other neurologists, in the face of these results that you expose, say nothing?

He invariably replies that he does not know.

- The disturbance of the movement [edit: idiomatic translation = *effect on motor symptoms*] has a great value for the researcher; it is evident to all and can be recorded with a video camera.
- Anyone can enter the site "ultimaedizione.eu" posted in 2015 (and which also has an English version), and the site "highdosethiamine.org" https://highdosethiamine.org/therapy-2/ and see the results of the care [edit: idiomatic translation = *treatment, therapy*] in the short and long term.
- If someone wants to search the internet for similar results they will not find them, they have never been published.
- In the literature it has never been written that a cure [edit: idiomatic translation = *treatment*] could bring Parkinson's disease to zero symptoms.
- Official science still says that non-motor symptoms are incurable [edit: idiomatic translation = *untreatable*], while Dr. Costantini says that they are the most sensitive to treatment.

Let's hope for the future.

Meanwhile, in Italy alone, about 20,000 Parkinsonians have died since 2013, after a long period of disability and suffering. Almost everyone would have escaped death and could have lived in a physical and psychological condition previously unthinkable."

To see videos at "ultimaedizione.eu" use these links

- *https://www.ultimaedizione.eu/2015/04/08/astonishing-parkinson-halted-by-vitamin-b1/40177/*
- *https://www.ultimaedizione.eu/videos-parkinsons-patients-treatment/*

In the videos, you can see that his patients are at varying degrees of disease progression and some are in the "severe range" and still show dramatic improvement by just adding thiamine/thiamin/vitamin B-1 to their standard PD prescriptions/meds.

Radio Interview with Dr. Antonio Costantini and Marco Colangeli

"High-Dose Thiamine: A Novel Promising Therapy for Parkinson's Disease"
[In Italian]
http://www.blogtalkradio.com/parkinsons-recovery/2018/05/23/high-dose-thiamine-a-novel-promising-therapy-for-parkinsons-disease/

PD symptoms before and during HDT Therapy

[Dr. Costantini's YouTube channel – patient videos used with permission]
https://www.youtube.com/channel/UCwsHIcP_h6QVWwd4uRg-HDQ?view_as=subscriber/

Video interviews of some of Dr. Costantini's Italian patients describing their experiences with HDT *[in Italian]*

https://www.ultimaedizione.eu/videos-parkinsonspatientstreatment/