

Question and Answer With the Experts

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University of Nebraska
Medical Center™



Frequently Asked Questions



Frequently Asked Questions

Is carbidopa/levodopa still the treatment of choice?

- There are many different types of treatments for Parkinsons Disease
- While levodopa may be one of the oldest, it is still the most effective medication!
- Treatment is tailored to the individual





Frequently Asked Questions

How do I know when I need to start using carbidopa/levodopa?

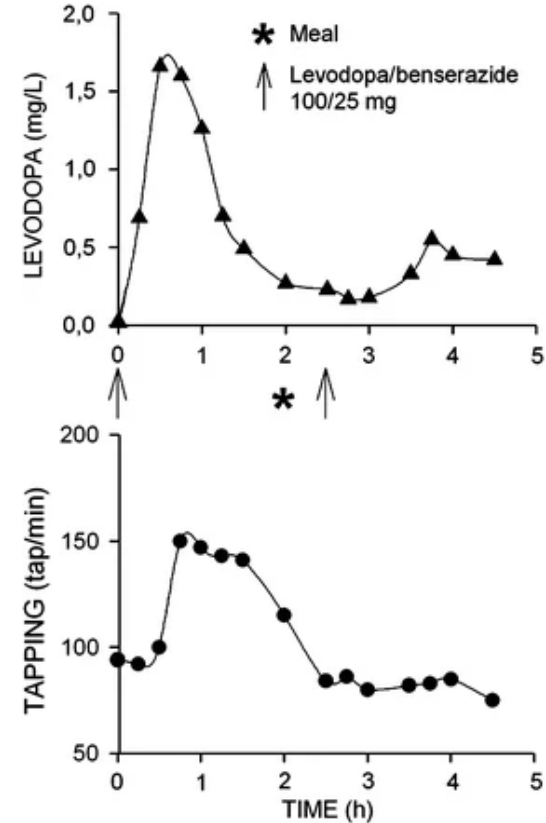
- Discuss with your doctor
- Things to consider
 - Severity of symptoms
 - Ability to function and stay physically active
 - Quality of life



Frequently Asked Questions

How important is it to take carbidopa/levodopa on an empty stomach?

- For some, VERY. For others, NOT AT ALL
- Levodopa competes with some proteins for absorption from the gut, sometimes reducing effectiveness if taken simultaneously
- Some people find increased benefit when taking either 30 minutes before or 1-2 hours following a protein-rich meal





Frequently Asked Questions

How can I best track ON and OFF times (motor fluctuations) to see if I need a medication adjustment?

- Many ways! Whatever is easiest for you
 - Good old pen and paper charts
 - A free template can be found at Parkinson.org
 - Example shown on the next slide
 - Multiple cell phone apps
 - "Parkinson Symptom Tracking"
 - "ADPA Symptom Tracker"
 - "Parkinson's Disease Manager"

Symptoms Log Example

TIME	MEDICATION	MEAL	SLEEP
5:00 am			
5:30 am			
6:00 am			
6:30 am			
7:00 am			
7:30 am			
8:00 am			
8:30 am			
9:00 am			
9:30 am			
10:00 am			
10:30 am			
11:00 am			
11:30 am			

List the symptoms you want to track - e.g., tremor, dyskinesia, anxiety - in the top row.
 When those symptoms occur, fill in the number that corresponds to the severity at that time.
 Write medication names and doses next to the times at which the person with Parkinson's takes them.

Put an X (or list foods) in the "Meal" column at mealtimes.

Put an X in the "Sleep" column when the person with Parkinson's sleeps.

0 = NONE

1 = SLIGHT OR MILD

2 = MODERATE, BOTHERSOME

3 = SEVERE, VERY BOTHERSOME

SYMPTOMS List 3			NOTES
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Frequently Asked Questions

How does THC and/or CBD affect PD?

- Proposition 437 recently passed in a landslide approval for use of medical marijuana in Nebraska
- Benefit for PD motor symptoms is anecdotal only. Clinical trials do not show consistent evidence of improvement
- Side effects include cognitive impairment, dizziness, fatigue, dependence



Frequently Asked Questions

Is there a link between diabetes and PD?

- Yes. Multiple large studies suggest an increased risk of developing PD by 30% in those with longstanding diabetes (>10 years)
 - Also evidence of increased risk for other neurodegenerative diseases (e.g., Alzheimers)
- Proposed cause: Insulin resistance, high blood sugars cause oxidative damage, chronic neuron inflammation and dysfunction
- Certain diabetes treatments are being investigated for neuroprotective benefits in Parkinsons Disease
 - Multiple GLP-1 agonists and DPP4 inhibitors

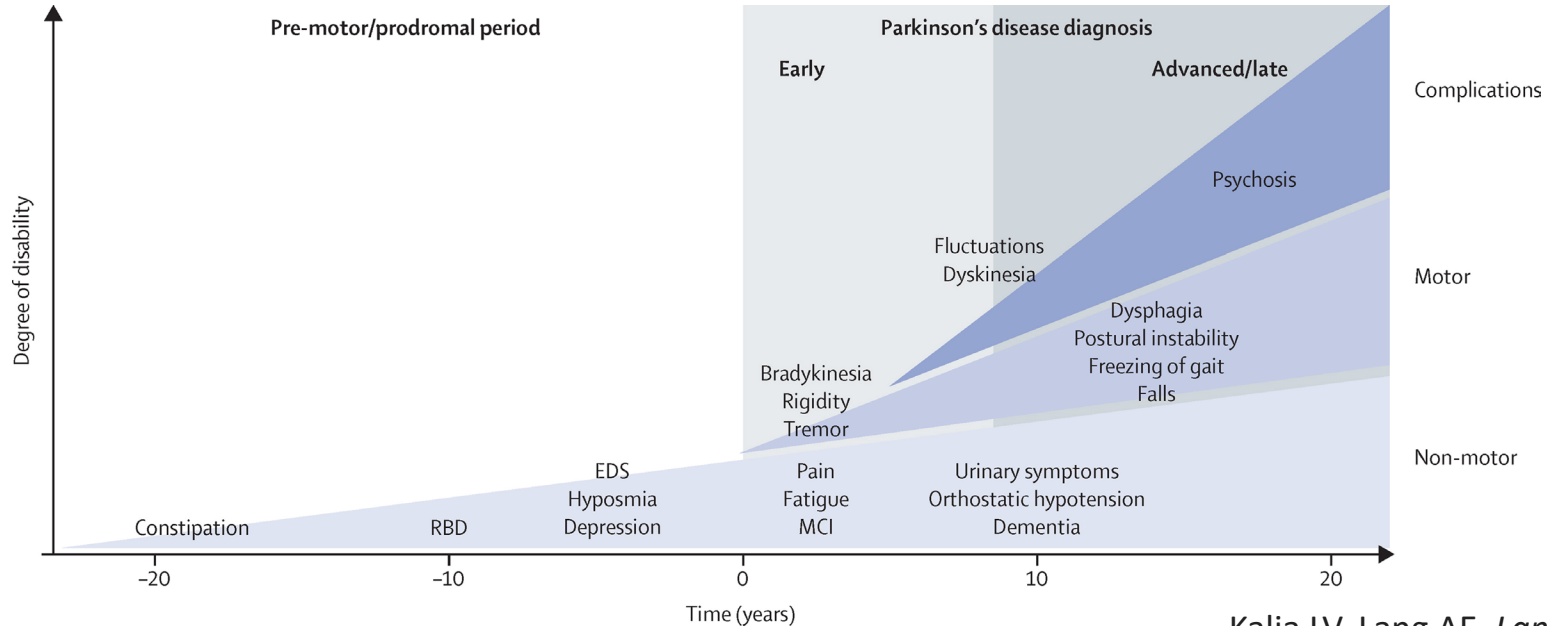




Frequently Asked Questions

How long before motor symptoms can one have PD?

- Non-motor symptoms can be present up to 20-30 years beforehand!

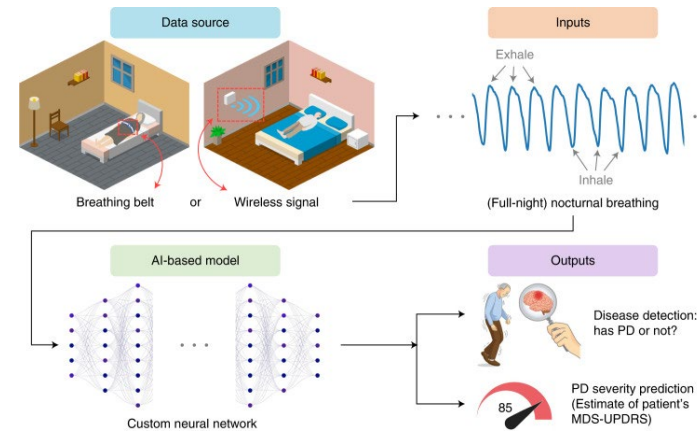




Frequently Asked Questions

Is Artificial Intelligence (AI) playing a role in the clinical treatment of Parkinsons Disease?

- Being developed for early diagnosis, tracking disease progression, and helping identifying targets for disease modifying therapies
- No practical clinical application yet





Frequently Asked Questions

Is DBS only good for tremors, or for other PD symptoms, as well?

- Rule-of-thumb: DBS treats all symptoms of Parkinsons Disease that are also treated by levodopa
 - Exception: can treat tremor and dystonia better than levodopa
- Three main indications for DBS in PD:
 - Levodopa helps, but there are severe motor fluctuations despite optimal adjustments to medications
 - Levodopa helps, but experience limiting side effects
 - Levodopa helps, but with refractory tremor

Frequently Asked Questions

I have toes curling in one foot compared to the other that is painful and makes walking difficult, is this common?

- Yes! Parkinsons Disease is sometimes accompanied by a symptom called "dystonia"
- Dystonia is overactivity of muscles causing abnormal posturing and sometimes pain
- Most commonly toe curling or ankle twisting, but can involve hands, arms, the body, neck or face!
- Sometimes related to dosing of levodopa

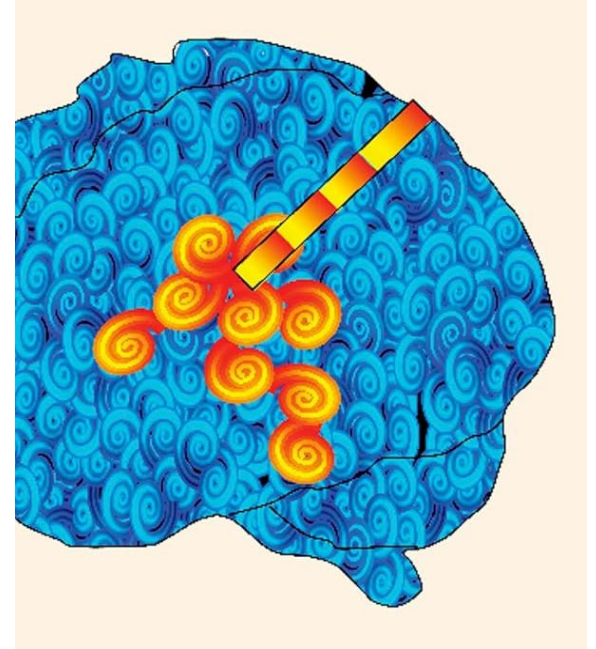




Frequently Asked Questions

How do you know how to adjust DBS settings?

- Same as medications! Based on symptoms and exam, ability to function
- Goal is to have satisfactory control of symptoms at the lowest possible settings to avoid side effects and preserve battery life





Frequently Asked Questions

Can DBS be used to reduce anxiety or other mood symptoms due to PD and medications?

- Not directly – but by reducing motor fluctuations and reducing medication burden, it often alleviates anxiety that is associated with these problems
- Severe, refractory Obsessive-Compulsive Disorder (OCD), a subtype of anxiety, is approved for treatment by DBS. But by stimulating a different part of the brain than PD
- Other anxiety treatment with DBS is experimental





Frequently Asked Questions

Is there anything that can be done to combat fatigue?

- Optimize the quality of your sleep – sleep hygiene
- Minimize other causes of fatigue
 - Address underlying sleep disorders
 - Screen for nutritional/hormonal abnormalities
 - Reduce medication burden, as able
- Take naps when needed

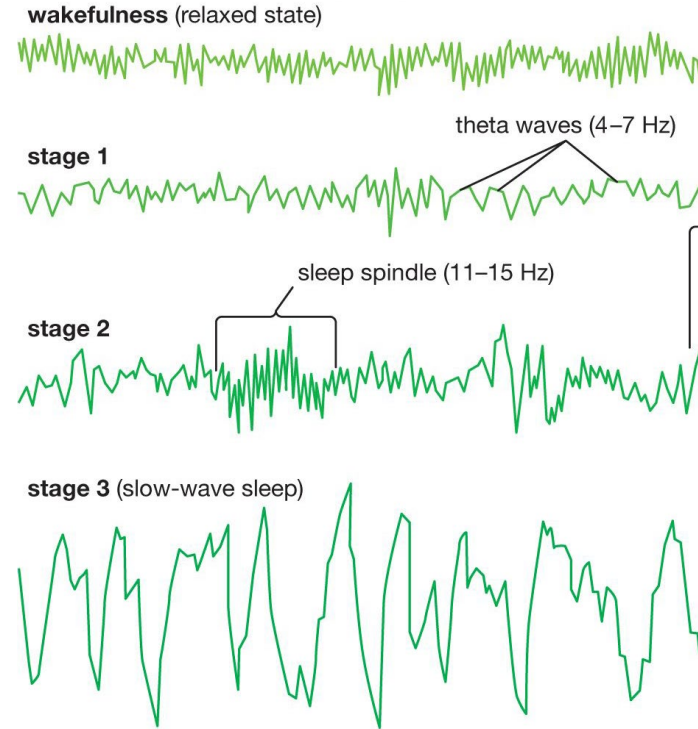




Frequently Asked Questions

Why do tremors stop during sleep?

- Almost all involuntary movements stop during sleep!
- The exact reasons are not known for certain, but the following likely contribute:
 - Reduced activity of motor control centers
 - Generalized slowing of brain activity
 - Increased levels of inhibitory/relaxing neurotransmitters
 - Decreased levels of excitatory neurotransmitters



Example of typical EEG tracings during wakefulness and sleep



Frequently Asked Questions

Any updates to the Leukine clinical trial with Dr. Gendelman?

- Completed a 33-month [2013-2016] phase I trial of safety and tolerability of Leukine (sargramostim) in PD patients
- Eventual goal of study is to determine if modulation of the immune system can slow progression of PD and other neurodegenerative diseases
- 5 patients completed the study without serious adverse events clearly attributable to the study drug
- A second, 48-week open-label phase I trial was just completed with 11 subjects earlier this month. Goals of study are safety/tolerability and immune system biomarker analysis. Results not yet published
- Considering phase II trial to determine efficacy for PD symptoms at some point in the future





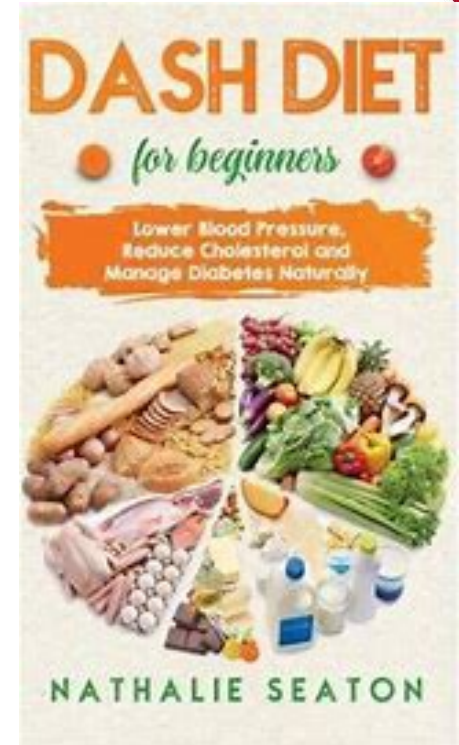
Frequently Asked Questions

Will eating certain foods/nutrients help produce more dopamine in my body?

- Unfortunately, no

Any nutritional suggestions to improve gut-brain health?

- Mediterranean/DASH diet

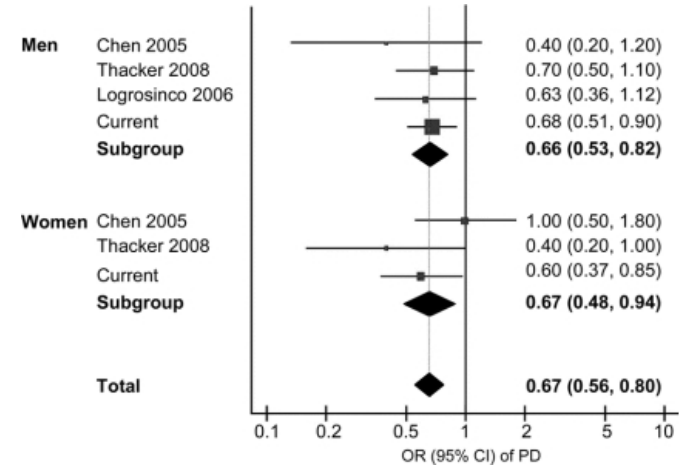




Frequently Asked Questions

What can be done to slow the progression of PD?

- **EXERCISE!**
- Regular physical activity has been shown to exert a neuroprotective effect, improving motor symptoms and cognition
- Regular, vigorous aerobic exercise starting in midlife has been shown to reduce risk of developing Parkinsons Disease by up to 33%



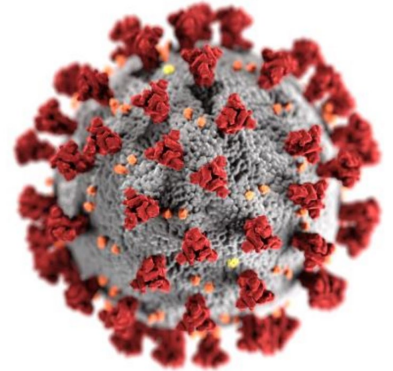
Xu Q, et al. Neurology. 2010



Frequently Asked Questions

Has COVID been associated with increased risk of developing PD?

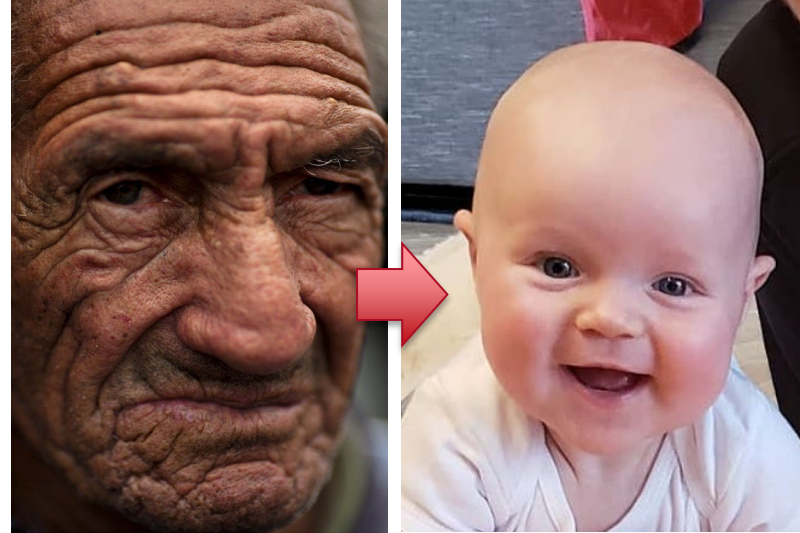
- Not yet...
- But, since COVID-19 remains a new illness, and PD is known to be a disease that develops slowly over years, *the relationship between them may yet unfold over time*
- Vaccination against COVID is recommended, as motor and cognitive symptoms are exacerbated during an infection and recovery



Frequently Asked Questions

Does Botox treat PD?

- Yes, Botox can be very effective at treating certain symptoms of PD refractory to medications
 - Dystonia
 - Bothersome drooling
 - Overactive bladder (urgency incontinence)
- Can also treat:
 - Chronic migraine headaches
 - Excessive sweating
 - And wrinkles!



Before Botox

After Botox



Frequently Asked Questions

Does Parkinson's Disease cause pain or arthritis?

- Reduced movement from rigidity and akinesia can lead to musculoskeletal pain
- Dystonia caused by PD can be painful
- Changes in posture can lead to pinched nerves
- Less commonly, nerve endings can be damaged (neuropathy)
- Occasionally "central pain" – can be an ill-defined, boring pain in certain areas or all-over



Frequently Asked Questions

What is dementia's impact on the expected duration of the disease?

- Dementia does not directly impact duration of disease, it is a symptom of the underlying disease
- Impulsivity and impaired attention can increase accidents [e.g., falls, aspiration, medication mismanagement] that can lead to increased mortality
- Presence of dementia reduces lifespan by roughly 1-2 years compared to those without. Highly variable!



Frequently Asked Questions

What are signs of Dementia with Lewy Bodies? What can be expected?



- Lewy Body Dementia Support and Wellness Group (patients and caregivers)
 - 3rd Monday of each month, 9:30am-11am at Heartland Neurological Therapy and Wellness Center
 - Julie Pavekla, APRN jupavelka@nebraskamed.com
- Lewy Body Dementia Caregiver Support Group
 - Zoom every 4th Friday from 1pm-2pm
 - Dawn Franklin, RN dfranklin@nebraskamed.com.

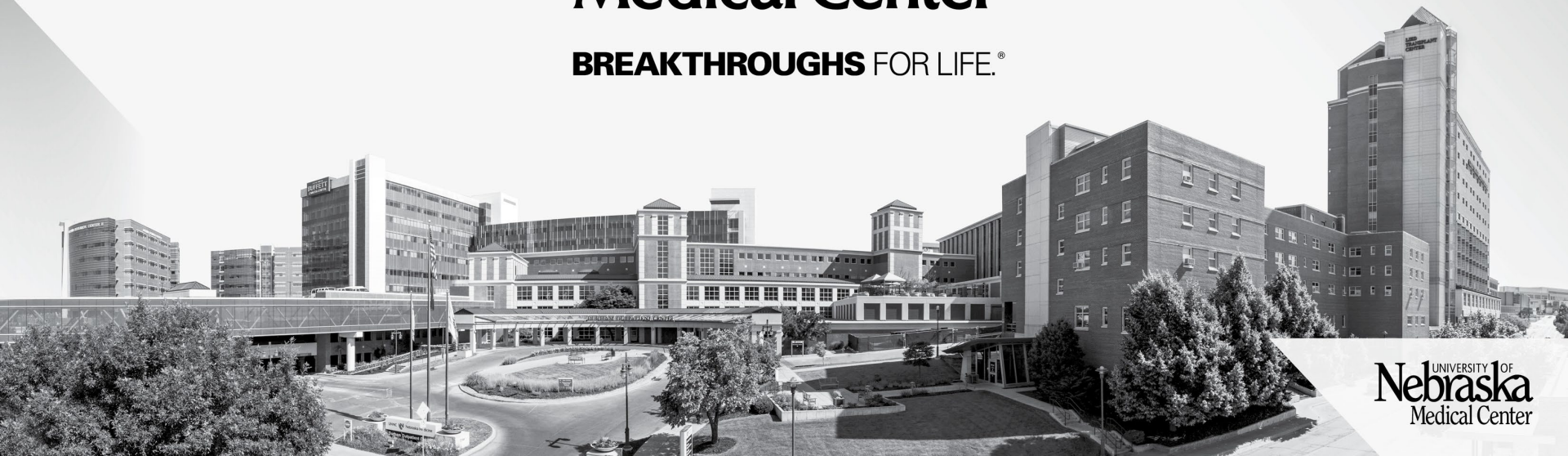


Thank you for coming!



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