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HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

Presenter Disclosures

Roy Nierenberg

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose
or list



living well with HD
Roy Nierenberg



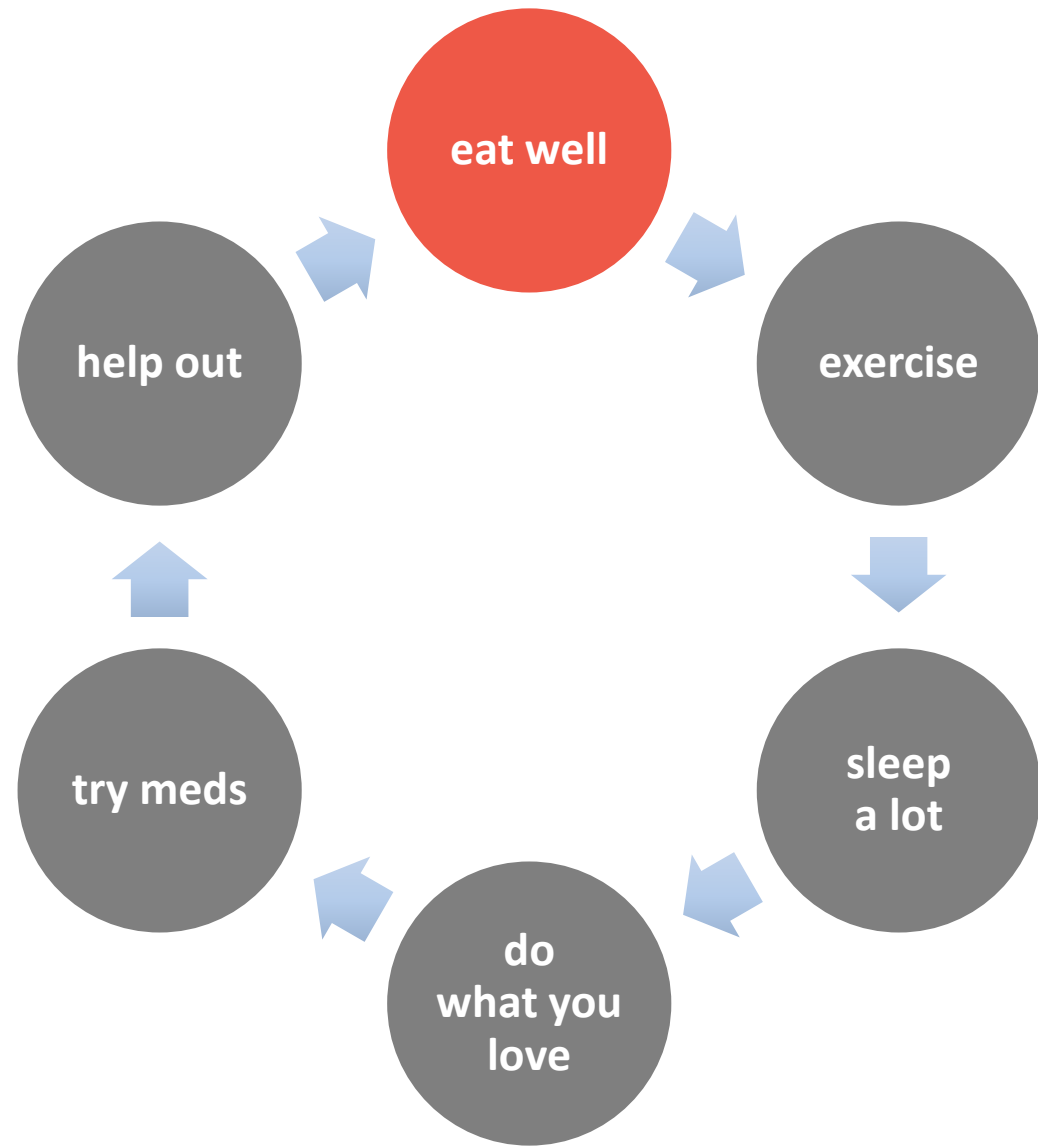
meet
Roy Nierenberg



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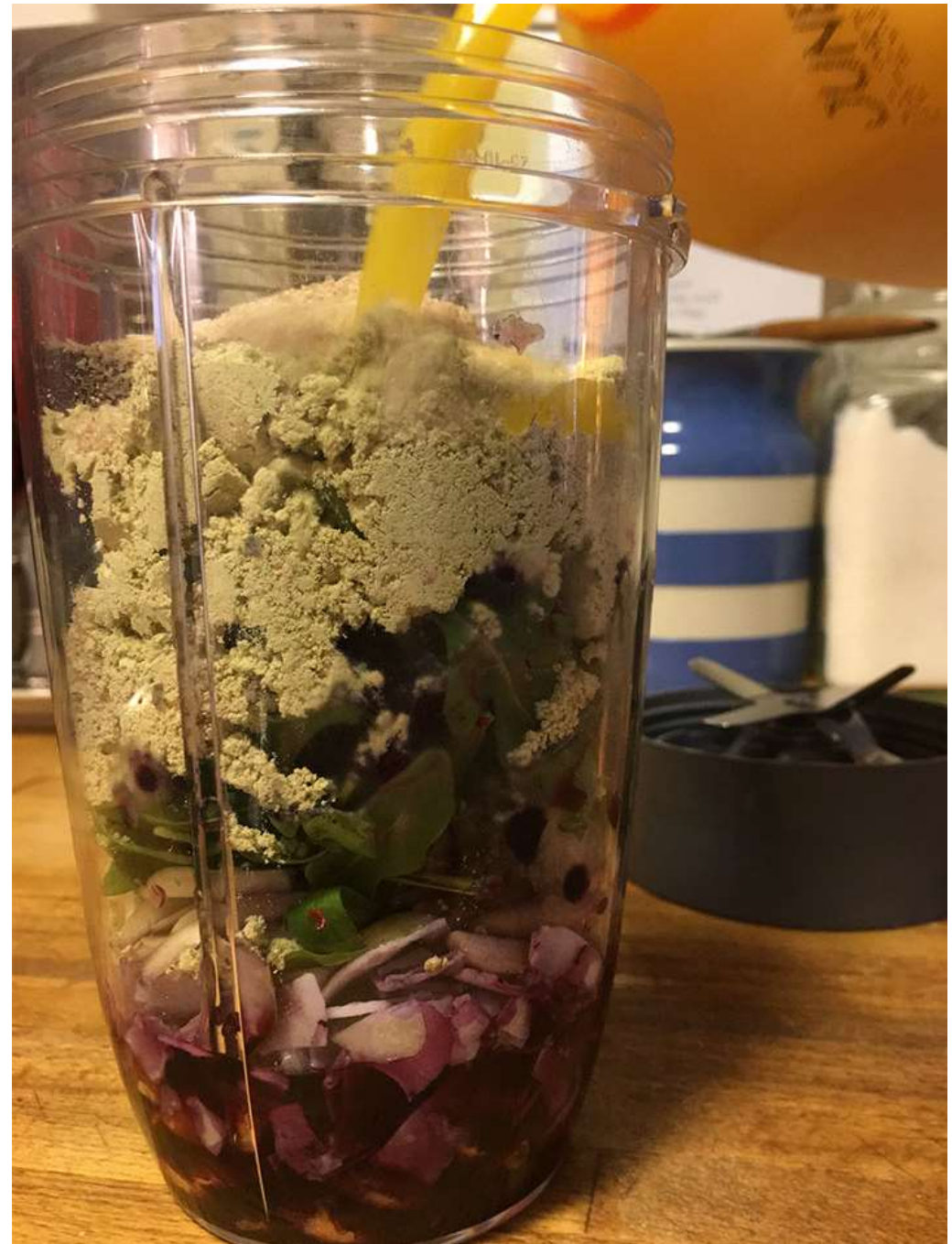
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eat
well

breakfast smoothie:

- almonds
- coconut flakes
- blueberries, frozen ok
- greens, like kale or beet greens
- protein powder
- orange juice



eat
well

lunch:

sandwich—

- whole grain bread
- salmon, broiled
- roasted beets
- mayonnaise
- horseradish!
- (keep it moist)



eat
well

....with a salad—

- red peppers
- cold, sautéed beet greens



eat
well

lots of snacks!

- protein drink
- almonds (again!)
- energy bars
- fruit
- red peppers
- juice
- sorbet



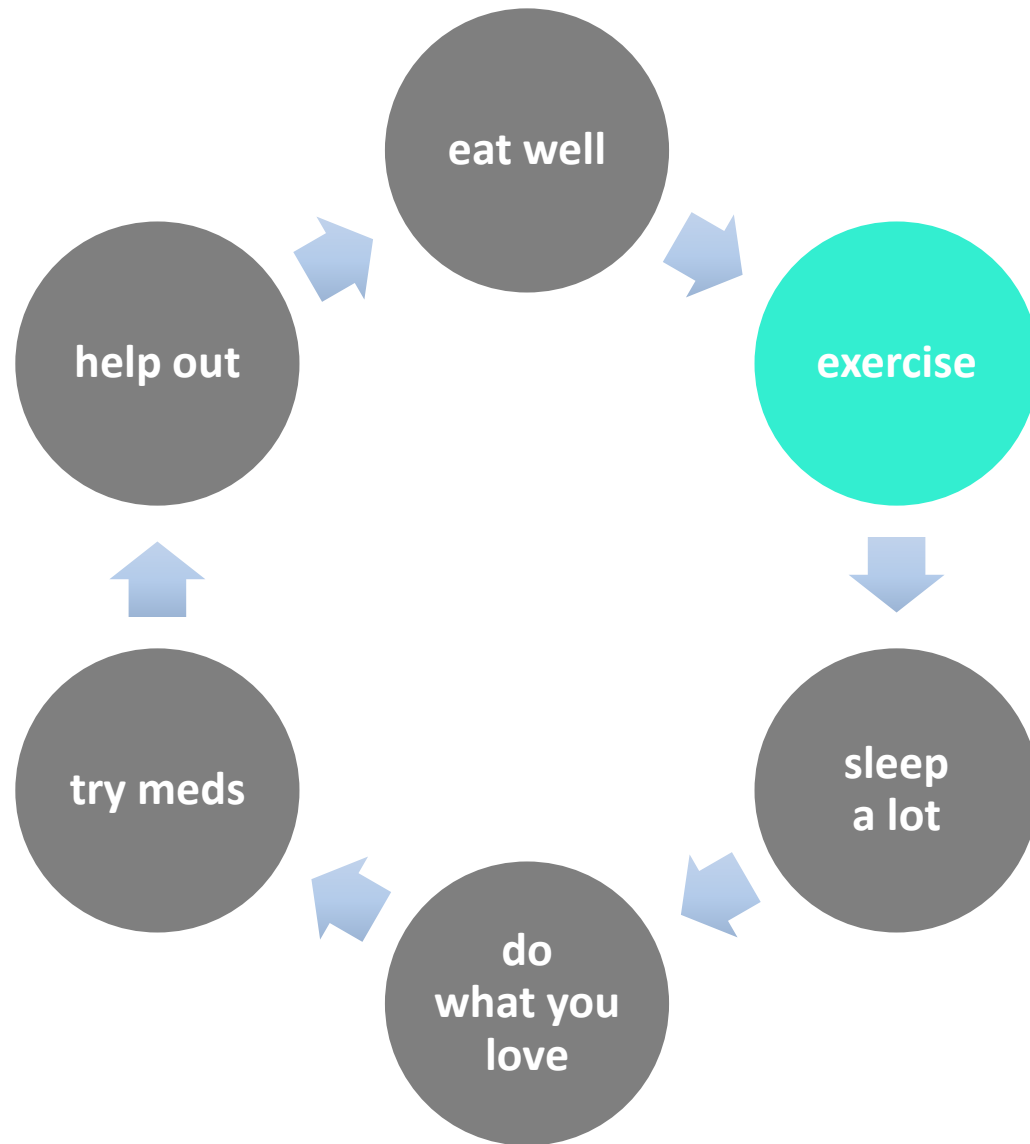
eat
well

dinner:

- whatever she gives me!



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exercise

biking helps with—

- strength
- balance
- my brain
- independence
- 28 gears—I do hills!
- saddle bags
- I fetch a few groceries
- it's ok to walk when I need to



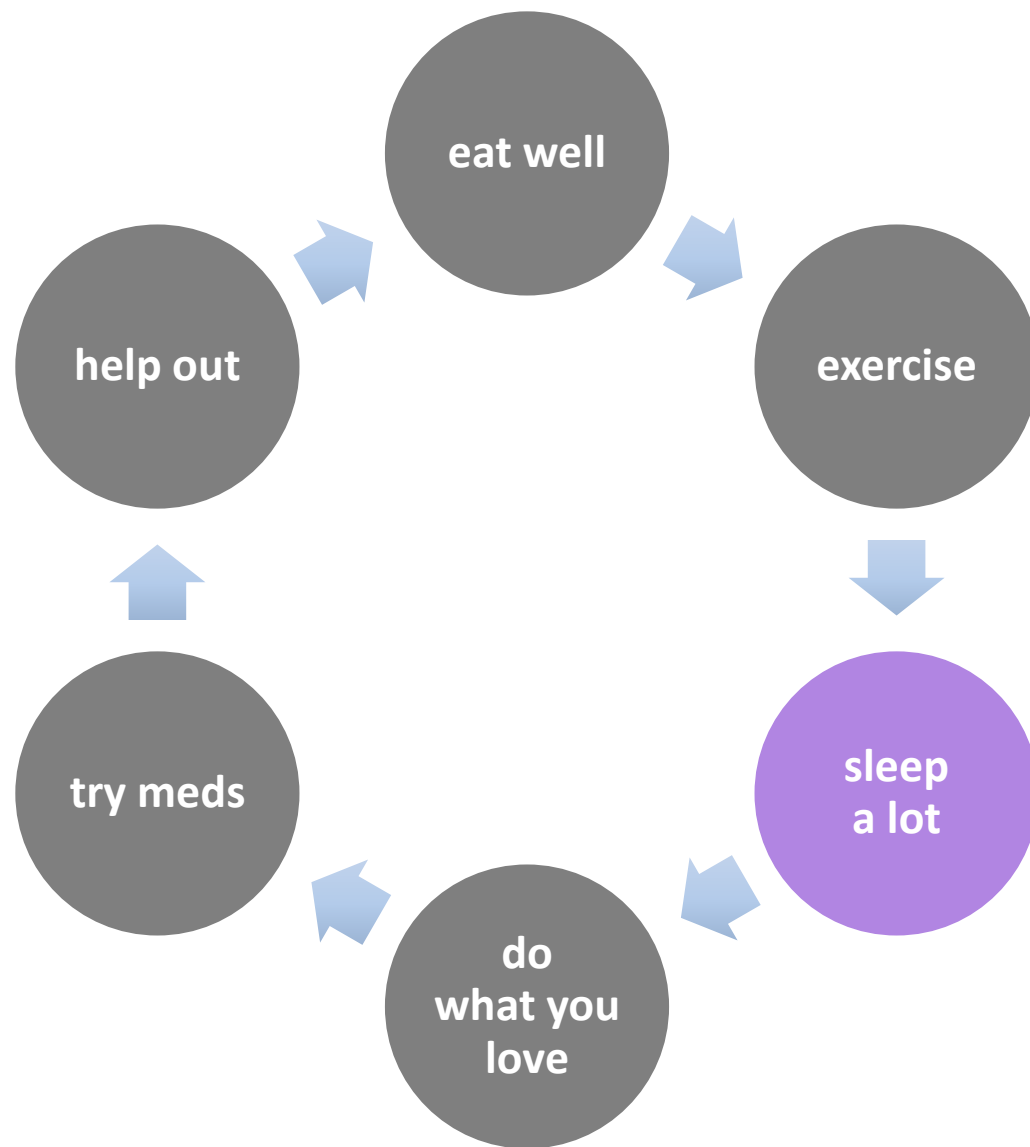
exercise

qi gong:

- good for balance
- part of a flock
- if I can't sleep!
- meditative
- 2x / wk +



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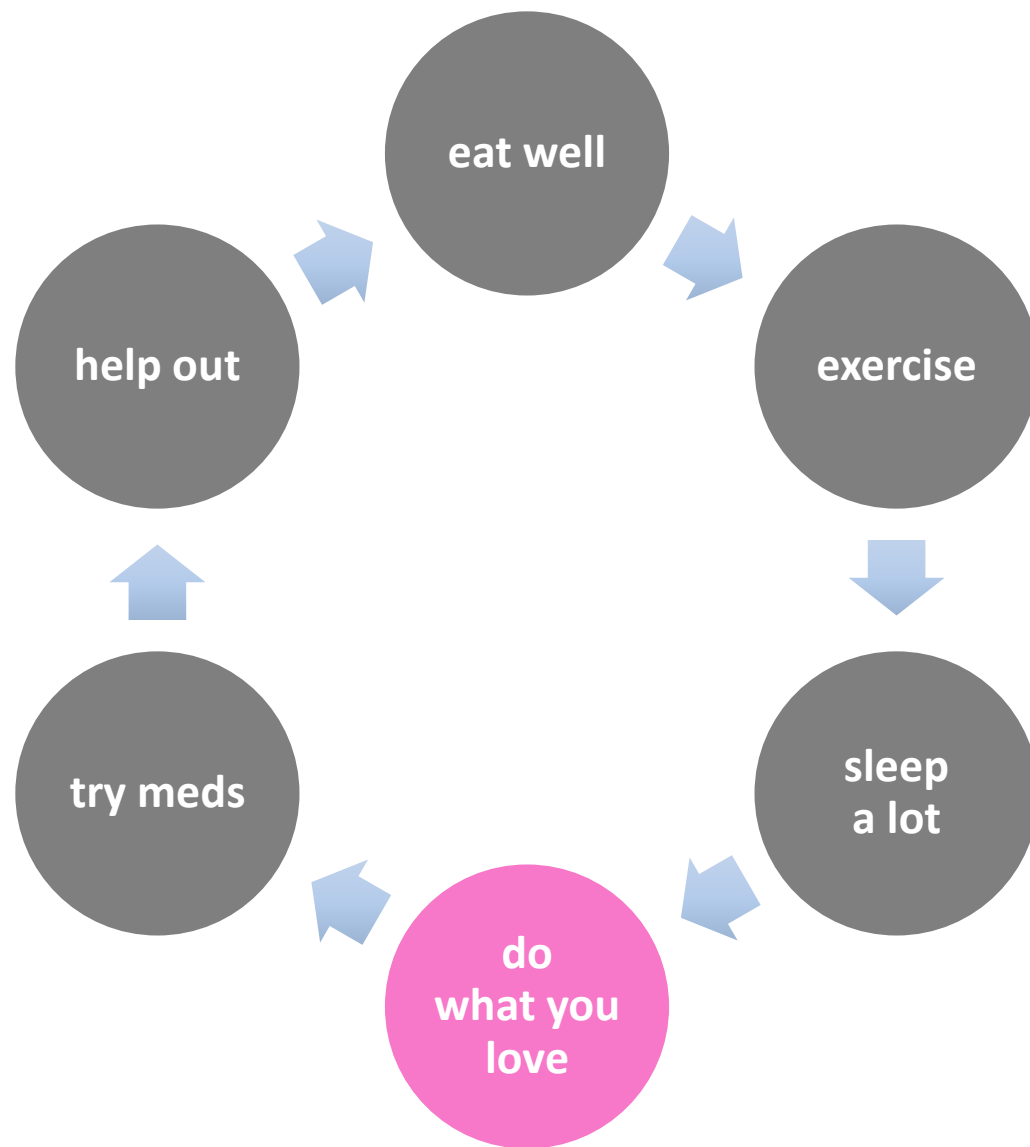
sleep

I sleep a lot!

- **10+ hours a night!**
- **melatonin helps me sleep**
- **less apathy / more energy**
- **neuroprotective**
- **I use my Jawbone UP to monitor my sleep**



living well
with HD



what
you
love

I sing in a community chorus

- we learn new music
- sometimes in other languages!



what
you
love

build community:

- I walk with my best friend Ed
- joined an HD support group
- go to therapy
- attend science lectures
- visit the Maker Faire!



what
you
love

advocate!

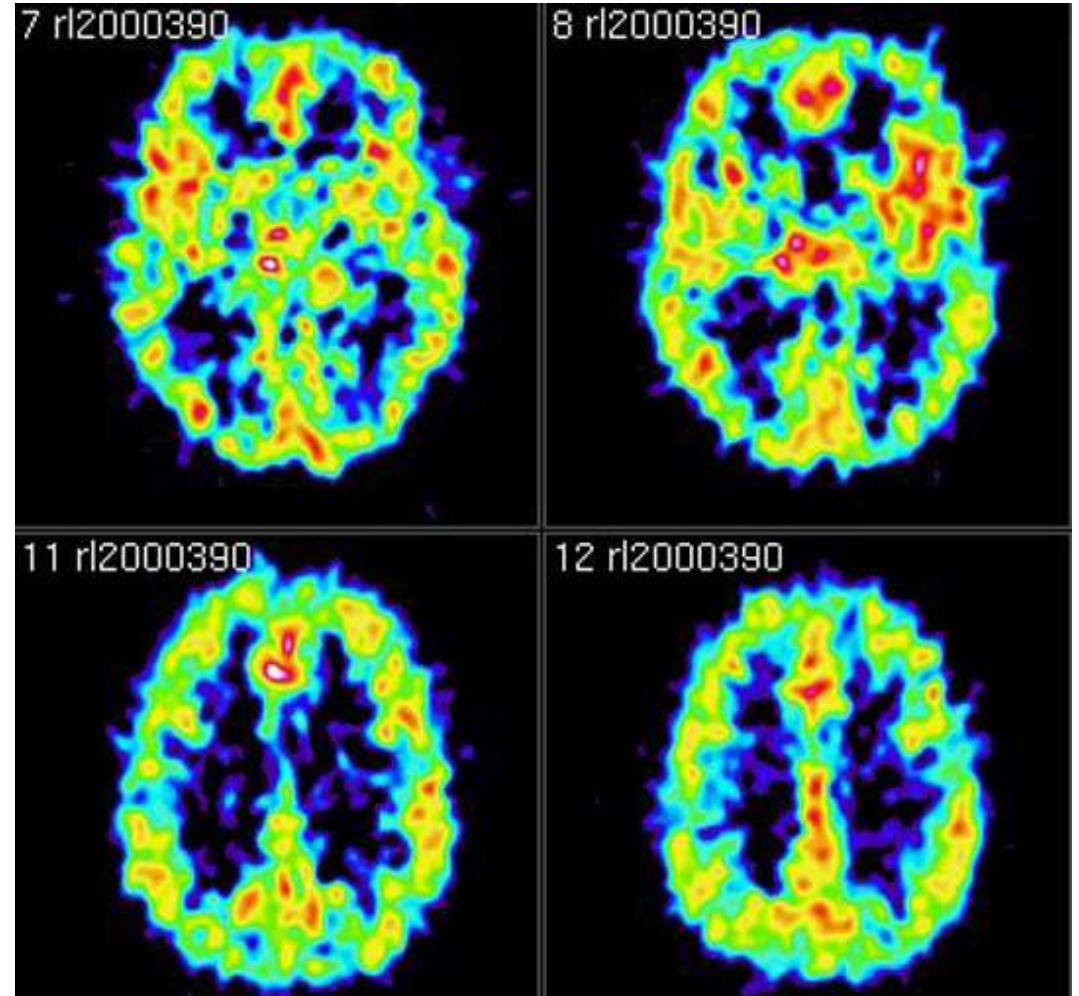
- I appeared before FDA on HD
- contacted my congressman about the HD parity act



what
you
love

participate in HD research:

- whole genome analysis in HD to find new therapeutic targets (Finkbeiner)
- Enroll-HD
- helps everyone!
- keeps me informed
- arranged donation of my father's brain to HD research
- mine will be available too!



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meds

try things!

consult your neurologist or
general practitioner!

...besides some of the
standardly prescribed drugs,
here's what's worked for me—



Verapamil —

- a calcium channel blocker, usually prescribed for high blood pressure or migraines
- promotes autophagy in animals with HD
- helped restore my creative thinking and reduced apathy



meds

Memantine (Namenda)

- usually for Alzheimer's
- makes me sharper



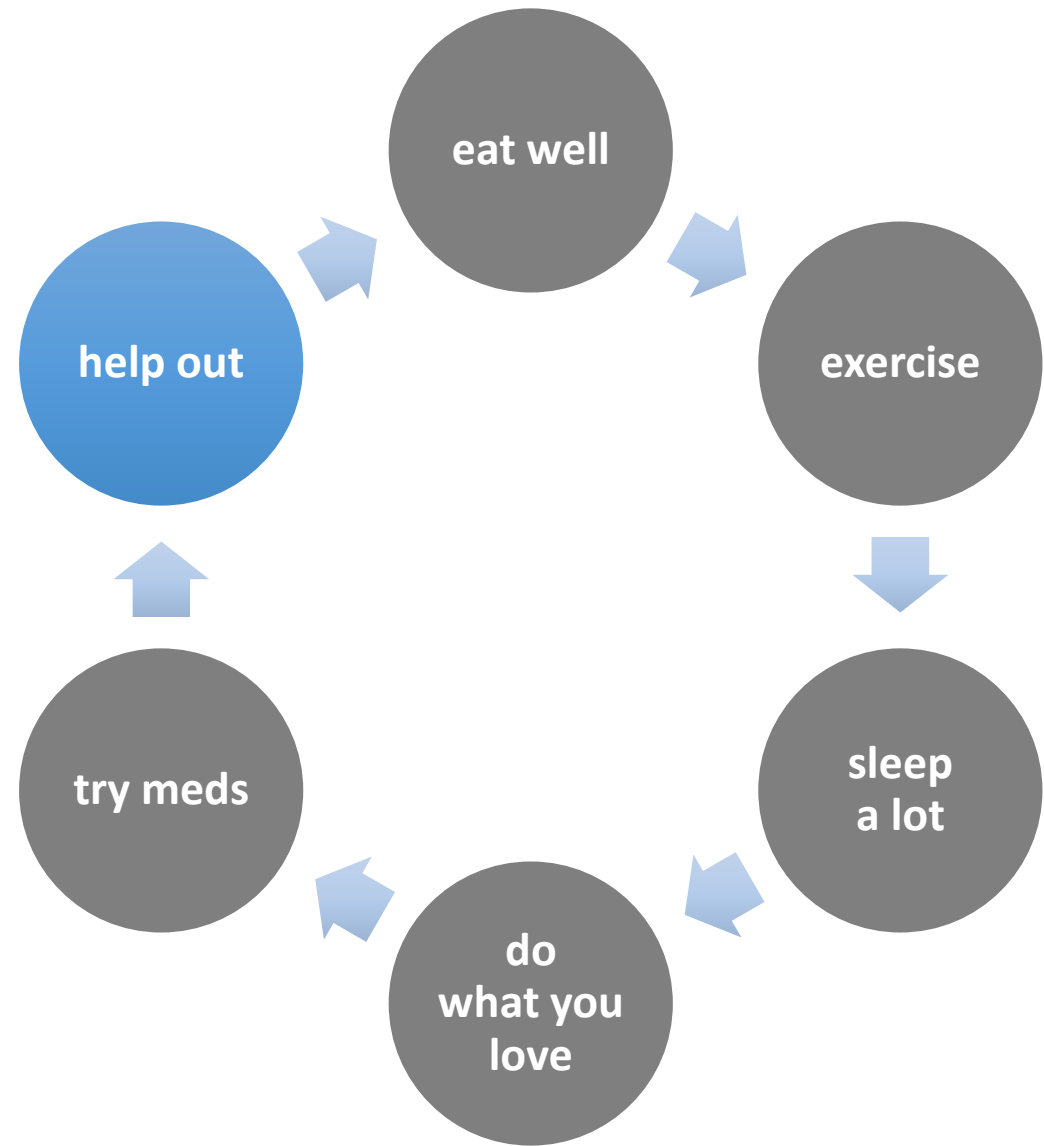
meds

melatonin

- a supplement, not Rx
- regulates sleep
- take it regularly at bedtime
- HD patients are naturally deficient in it



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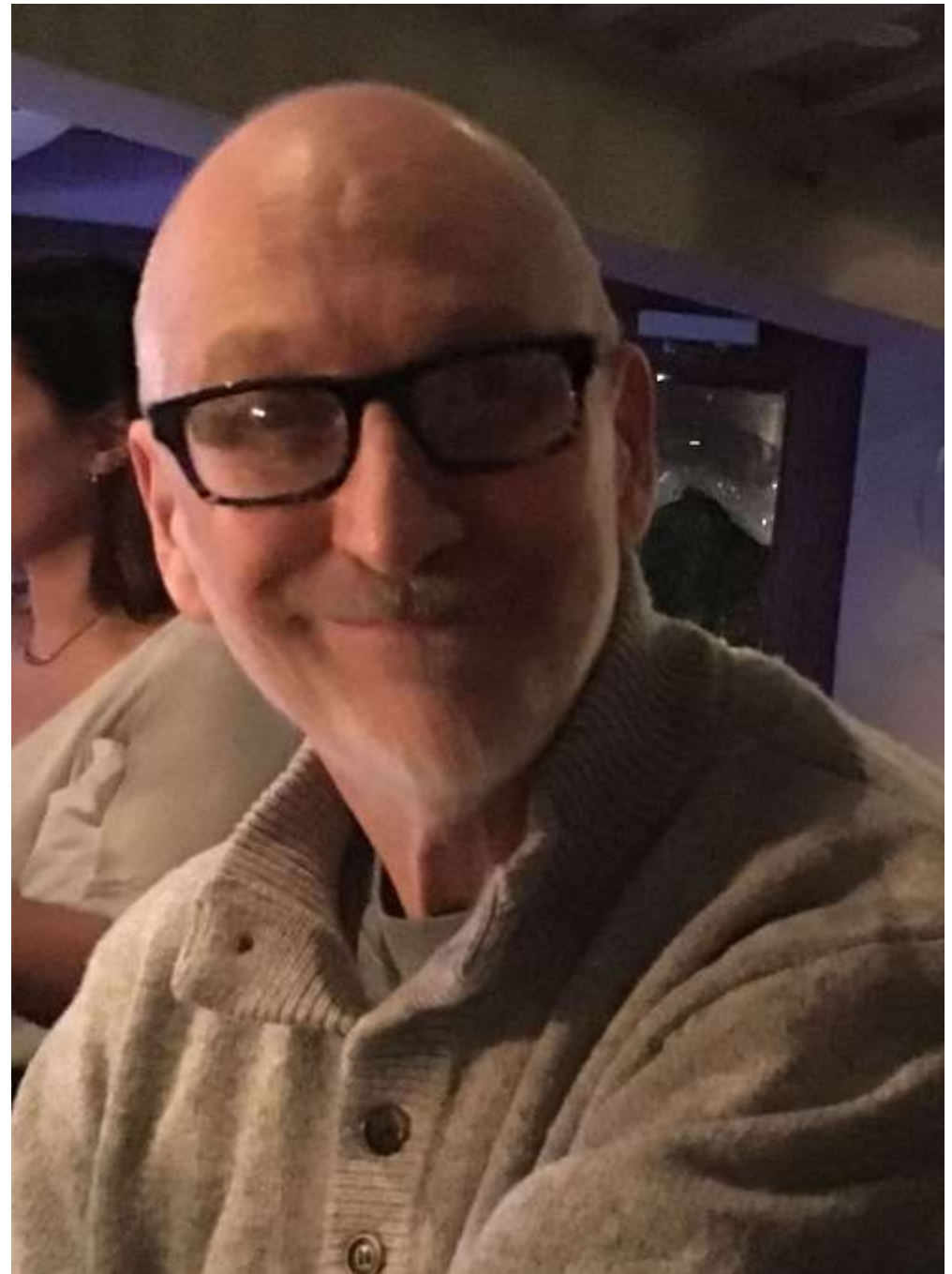
help
out

trust your caregiver!
caregiving is hard—

- how can you help?



questions?



resources

Heros:

Sara Riggare

<http://www.riggare.se/1-vs-8765/>

https://www.youtube.com/watch?v=0vG_ZylSWKo

Exercise:

The best exercise for aging muscles:

https://www.nytimes.com/2017/03/23/well/move/the-best-exercise-for-aging-muscles.html?_r=0

Qi Gong:

<http://www.wenwuschool.com/>

Health benefits of Qi Gong:

www.nga.org/assets/docs/Know-the-Evidence-FINAL-1.pdf

Berkeley Community Chorus:

<http://storychorus.org/spirit-of-bcco/>

<http://storychorus.org/community-brain-science-power-of-music/>

<http://storychorus.org/my-philosophy-of-choral-singing/>

Sleep:

Jill Bolte Taylor, My stroke of insight

https://www.ted.com/talks/jill_bolte_taylor_s_powerful_stroke_of_insight

Meds:

Verapamil

http://web.stanford.edu/group/hopes/cgi-bin/hopes_test/verapamil/

Where to donate your brain:

<http://www.nybb.hs.columbia.edu/>