NOTES ON EXERCISE, LOW CARB LIVING, AND DEGENERATIVE DISEASE

By Dag Forssell, June 30, 2020.
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Friends,

I have put together this report to reassure myself, Christine, and people important to us that our efforts to mitigate Christine's Parkinson's disease are on target, not ineffective or dangerous. A low carb, high fat, ketogenic lifestyle is understood by many to be unhealthy and unpalatable. Our readings, experience to date, and search of scientific literature proves just the opposite.

My mother taught me and lived her motto: *Nothing comes into a closed hand*. In the spirit of an open, sharing hand, part of our study and action calls for sharing with our physicians, therapists, family and friends so they will understand us, and we get feedback. Thus this report. Well, more than that. Putting this report together has led to a journey of discovery as it forces a careful review of our understandings—what we are doing and why. How it all hangs together. It is important that the two of us are on the same page—want the same thing for the same reasons. And equally important that our understandings are well founded. Serious challenges welcome!

While our compelling motivation for study and action is Parkinson's disease, I think that what we have found about exercise programs, low carb living and degenerative disease in general can be of interest to anyone, especially seniors and people with insulin resistance and/or neuro-degenerative disease, so I am sharing with friends in our Swedish community, friends where we live now, friends and relatives around the world, and friends in our Parkinson's support groups.

I hope our friends in other countries will have a look at the Swedish exercise videos (next page), and let me know if your (non-commercial) TV station (such as BBC) has produced and archived exercise videos of a similar nature (that I might download, of course).

This report has evolved for two months. Time to create a ***Table of Contents***.

Our ***Home gym*** (this page) came first. At the end of 2019, our Holiday Report provided an account of our introduction to a keto lifestyle, and our realization that Christine has Parkinson's.

I started these pages in late April to share info on ***Exercise*** p. 2, went on to search YouTube for info on our ***Keto lifestyle*** p. 3, which expanded to ***Degenerative disease*** p. 4, and ***Scientific research reports*** p. 4. The scientific reports led me to realize that a keto lifestyle mitigates Parkinson's disease, perhaps even more than exercise, so I prepared a proposal for a large-scale educational research study: StudyKetoParkinsons.pdf. ***Parkinson's*** is discussed on p. 6, followed by ***Sinemet*** p. 7, ***Neurology*** p. 8, ***In conclusion*** p. 9, and ***Downloading*** p. 10.

Home gym

For years, we had exercise equipment in our garage. Now we have a bedroom gym geared to video. We have it set up so we can see our therapist whether we stand up, sit, or lie down. I have placed our laptop on a shelf and step up to adjust its camera angle as needed so our therapist can see Christine clearly no matter where we are. Conference video has to work both ways.

Exercise

Exercise slows the progress of Parkinson's. Exercise is now more important to us than ever.

Physical therapy/exercise with personal attention

Even before we moved to Menlo Park, we signed up to attend a group exercise program at Avenidas in Palo Alto with Jenni Castaldo. We liked Jenni so much that once we moved, we asked her to work with us at home as well. While sheltering in place, we train with Jenni using the Zoom video conferencing program.

When Christine was diagnosed with Parkinson's and evaluated by a neurologic physical therapist, she was referred to an exercise class for Parkinson's patients, hosted by the Redwood City Veterans Senior Center, conducted by Theresa Najjar, PT, DPT, MS. We currently attend Theresa's Zoom exercise classes for seniors four days a week. These vigorous workouts incorporate moves that help our nervous systems stay in good shape.

Theresa and Jenni are both good at multitasking. They exercise with us, demonstrate and explain at the same time, with incredible stamina. They manage to keep an eye on us and other participants, watch for difficulties and clarify instructions as needed. They have become good friends.

Swedish recorded exercise programs

In March and April, Swedish TV featured thirty 20-minute home exercise sessions: https://www.svtplay.se/hemmagympa-med-sofia (SVedishTvPLAY homegym-with-sofia).

The SVT archive won't linger forever, so I downloaded Sofia's videos. See page 10 in this pdf.

Christine and I are becoming connoisseurs of exercise programs. Personal attention is by far the best, but I think these SVT videos with Sofia are worth sharing for two reasons:

1) Our Swedish speaking friends can enjoy them. Others may find the demonstrations enough.

2) The quality is high in several respects. Sofia is good, demonstrating all the way through, with front and side views, while simultaneously explaining what to do, and not. Such stamina! Production is excellent with good lighting, Sofia wired for sound, and excellent photography that follows Sofia smoothly with the occasional close-up. Sofia looks into the camera so you feel as if she talks only to you. The thing she cannot do is see you, encourage and correct you. That's our personal therapist's edge. Funny thing to us is that her setting is so Swedish. The apartment, the furnishings. You think you are in an IKEA showroom ☺

In case you are curious about Sofia (she attended the same Phys Ed college Christine did) you will find her story HERE. You can right-click in Google Chrome to ask for a decent translation into English. Swedish friends may enjoy an hour long INTERVIEW, discussing this exercise program as well as Sofia's recent Swedish book *Nystart* about seniors and exercise.

Rock Steady Boxing (RSB)

Exercise drills adapted from boxing turn out to be especially beneficial for Parkinson's patients because they incorporate neural exercise, rapid movement, balance. To provide an alternative to classes nationwide during Shelter in Place, Rocksteadyboxing.org posted **videos on YouTube**. As of May 29, this holds 69 short videos. You can also search YouTube for RSB ROX.

Keto lifestyle: Low carb, high fat, adequate protein

In mid-2018, long before Christine was diagnosed, she complained to our physician that she was tired all the time. He suggested we read his favorite book, *The Art and Science of Low Carbohydrate Living*. Our 2019 **Holiday Report** tells the story. The books and DVDs I review in this Holiday Report suggest a relationship between insulin resistance, carbohydrate intolerance, and several degenerative diseases. Please read this Holiday Report as an integral part of this report.

Searching YouTube for info about Parkinson's and ketosis, I found plenty of anecdotal reports from people who say they cured themselves, more or less. But Parkinson's comes in so many different guises, you can't know what went on. There are interesting testimonials connecting ketosis with Parkinson's. Skepticism and careful evaluation is called for. Keto is fast becoming a marketing buzzword, spawning strange product offerings such as Keto Protein—a contradiction in terms. There is indeed much misleading info on the Internet, some designed to scare you.

One find led me to *Emerging Science of Carbohydrate Restriction and Nutritional Ketosis*, a scientific conference. I downloaded it all from YouTube, with presentations already nicely numbered. For how to download a playlist like this, see p. 10 in this pdf.

Now I had the entire 2019 Ohio State University conference with solid, scientific information about nutritional ketosis and its benefits for seniors. The presentation that led us to the conference is #2 *Ketogenic Diet and Aging* by Dr. Jon Ramsey of UC Davis, which shows evidence of improved cognitive ability, stronger muscles, and longer life.

Oh, just mice you say... But move on to #12 - Dr. Stephen Cunnane: *Brain Glucose and Ketone Metabolism in Alzheimer's Disease*, and you see similar improvements in cognitive ability in people whose brains have an ample supply of ketones, our brains' preferred fuel.

Be sure to watch #3 - Drs. Volek and Phinney. They provide an overview, the history of it all, define what is Keto and what falls short, with suggestions on how to make keto please your palate.

#4 - Dr. Dominic D'Agostino suggests what keto will mean to various medical disciplines.

There is much to learn about insulin resistance, pre-diabetes*, carbohydrate intolerance, obesity, degenerative diseases, and ketone metabolism—the history and the explosion of research in the last 25 years. Presentations in this conference challenge decades of institutionalized, widely believed misinformation, including government sponsored advice regarding nutrition.

Doing keto right to take full advantage requires careful study, a willingness and time to rethink what you thought you knew. It is by no means a slam dunk. But given the excellent books I review in the **Holiday Report**, and the many beautiful cook books available to you, it is not difficult either.

* The CDC says that "approximately 88 million American adults—1 in 3—have prediabetes. What's more, more than 84% of people with prediabetes don't know they have it."

Degenerative disease

Insulin resistance, cell metabolism, food choices

The Art and Science of Low Carbohydrate Living (2011) by Drs. Jeff Volek and Stephen Phinney, is written for physicians. More than one third of the 300 pages deal with our physiology, and another third with clinical applications. What you learn from Chapter 3, *The "Modern" History of Carbohydrate Restriction*, is shocking. Christine and I read the book together, discussing it sentence by sentence as needed. The information presented here is detailed and, to us, compelling. We have read it twice but we forget. Now time for a third reading. We came to understand that development of insulin resistance/carbohydrate intolerance has far-reaching consequences, leading to several different degenerative diseases.

We read *Fat for Fuel* (2017) by Dr. Joseph Mercola the same way. This book reviews much of the same sorry history and provides more insight into cell metabolism, focusing on mitochondria. Again, much discussion of degenerative diseases.

Both books provide much critical comment on the Food Pyramid, promoted by the USDA.

Christine and I realize that it is up to us to learn how to improve and maintain our health for the duration.

We sure are glad our physician pointed us to the book on Low Carbohydrate Living ☺.

Scientific research reports

Degenerative disease and low carb lifestyle

Given our understanding of and experience with a low carb lifestyle, I wanted to find more scientific information. A friend pointed me to **scholar.google.com**. Here I quickly found that I could search for word pairs such as parkinsons and ketogenic, and as search results appeared I could see ketosis connected to neurological disorders, mitochondria, migraines, multiple sclerosis, inflammation, obesity, and more.

I selected 17 scientific papers for the table on the next page. You can copy the title of a paper, paste it into scholar.google.com, and find the reports. The last line of descriptive text provides links, such as "All xx versions". Click on that to see which version is a PDF file.

These reports all suggest that our low carb lifestyle is beneficial. A ketogenic diet provides energy to neurons and mitochondria, diminishes inflammation, and supports regeneration.

The two studies, (02) and (06), are barely noted at parkinsons.org. I asked and was told:

> Hello Dag, Thank you for contacting the PF Helpline. I do not know if there are further studies going on about the keto diet and PD. Unfortunately, we don't have anybody at PF knowledgeable about further research about this study. The Parkinson's Foundation does support research, but we do not come up with the research questions. Scientists from across the country submit their work and hypotheses and we select from those to fund. So far, no one has submitted a study they are working on about the keto diet.

I find myself inspired to inject a proposal in this report, dealing with study and consideration of keto for Parkinson's, and to suggest a large-scale study: **StudyKetoParkinsons.pdf**

#	Type	Year	Title
(01) *	Book *	2017	Chapter 18: Dietary Therapy for Neurological Disorders Book, 425 pages: Ketogenic diet and metabolic therapies: Expanded roles in health and disease. Oxford Univ Press.
(02)	Study	2005	Treatment of Parkinson disease with diet-induced hyperketonemia: a feasibility study
(03)	Review	2006	Neuroprotective and disease-modifying effects of the ketogenic diet
(04)	Review	2016	Relationships Between Mitochondria and Neuroinflammation: Implications for Alzheimer's Disease
(05)	Review	2012	The ketogenic diet as a treatment paradigm for diverse neurological disorders
(06)	Study	2018	Low-Fat Versus Ketogenic Diet in Parkinson's Disease: A Pilot Randomized Controlled Trial
(07)	Review	2014	Neuroinflammation in Parkinson's disease: Role in neurodegeneration and tissue repair
(08)	Review	2015	Modulatory role of ketogenic diet on neuroinflammation: A possible drug naïve strategy for treatment of Parkinson's disease
(09)	Review	2019	Role of ketogenic diets in neurodegenerative diseases (Alzheimer's Disease and Parkinson's Disease)
(10)	Review	2014	Ketogenic diet in neuromuscular and neurodegenerative diseases
(11)	Review	2018	Ketogenic Diets for Adult Neurological Disorders
(12)	Study	2012	Dietary ketosis enhances memory in mild cognitive impairment
(13)	Review	2012	Mechanisms of Ketogenic Diet Action
(14)	Review	2009	Neuroinflammation in Parkinson's disease: A target for neuroprotection
(15)	Review	2014	The Emerging Role Of Nutrition in Parkinsons disease
(16)	Review	2017	Alpha-synuclein: Pathology, mitochondrial dysfunction and neuroinflammation in Parkinson's disease
(17)	Review	2011	Mitochondrial dysfunction in Parkinson's disease

* When you search for the title of chapter 18 in (01), you get the entire book as pdf. If you search for the book title you get to google books, and from there to book stores.

Parkinson's and exercise

Note that (04) provides a discussion of exercise, showing that it has many of the same brain healing effects as the ketogenic diet. This explains to us why exercise delays the progression of Parkinson's disease.

With exercise and keto together, Christine gets a double dose of healing ☺

Our research won't stop here. We will look for more specifics on exercise. I just found and downloaded four studies and two reviews. A quick scan tells me I am going to learn about the effect of intensity, among other things.

Parkinson's

What is Parkinson's?

Parkinson disease (PD) is a complex movement disorder in which the symptomatology, severity and progression vary substantially among patients. (review)

That means a bewildering, sobering array of symptoms with unpredictable progression. Not that easy for anyone to diagnose, research, understand causes for, or develop treatment for.

Christine's symptoms

- **Movement disorders**
  The typical symptoms of Parkinson's are shaking and stiff joints. Christine had none of these and still does not. She developed restless leg syndrome perhaps six years ago. Later came balance problems and handwriting that got smaller and smaller, even from the beginning to the end of her signature.
- **Smell**
  Christine has complained of diminished smell for several years
- **Pain**
  Pain in butt muscles and the lower back led to numerous visits to an orthopedic sports medicine specialist, MRI scan of the lower back, and injection of cortisone into the periformis muscle. All to no avail. Her 1961 injury with loss of the medial left knee meniscus led to arthritis. This was remedied with a left knee replacement in November 2016. The knee is doing fine—no pain there. Other pain and restless leg continued, especially at night. Christine found that stretching exercises, walking around and then cycling on a stationary bike would help her settle down and go back to sleep.

  Over-the-counter pain medicine did not work. Christine has tried prescription pain medications along the way. None made any difference. What relieves pain now is Parkinson's medication.

Diagnosis

Christine fell on Christmas eve 2017. We asked our primary physician for an evaluation. We were referred to a neurologist who noted Christine's balance difficulty but could not make a diagnosis. An MRI brain scan revealed moderate Small Vessel Disease. In itself, this was inconclusive, as some 95% of people aged 60–90 have this condition of microscopic blood vessels clogging up. Obviously, the implication is that the brain loses functionality, but how and where is not so obvious.

So our neurologist offered a test: Try Sinemet, increasing gradually, to see if that helps. Christine not only tolerated Sinemet, she improved dramatically. Now our neurologist declared that Christine is Parkinsonian (no shakes) or more simply, she has Parkinson's Disease.

About Sinemet

What defines a collection of symptoms as Parkinson's Disease more than anything is the response to Sinemet, one of the brand names for medication with the main ingredient Levodopa, an amino acid, a precursor to the neurotransmitter dopamine.

Normally, dopamine is secreted by the collection of brain cells called Substantia Nigra, illustrated in a blog article by Dr. Georgia Ede. Dr. Ede suggests that Alzheimer's and Parkinson's both have lots to do with Insulin resistance. Scroll down to the heading *Parkinson's Disease as a Metabolic Disorder*.

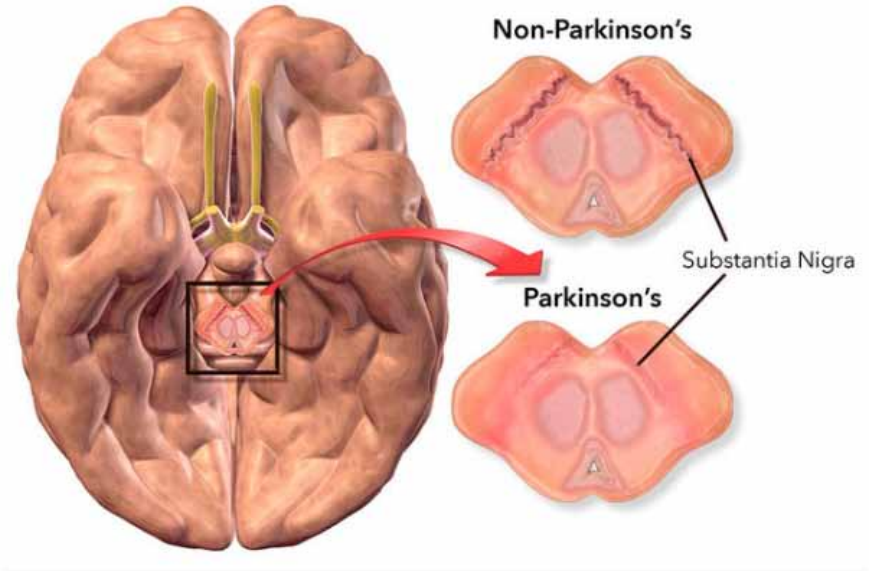


Illustration from Dr. Ede's blog. Source: Bruce Blaus/Medical gallery of Blausen Medical 2014

Levodopa is an amino acid. For best effect, it should be taken separately from a protein meal, because proteins are broken down to amino acids and peptides which would compete with it for assimilation in the small intestine. Christine keeps the Levodopa in Sinemet pills well separate in time from other amino acids.

Minimizing Sinemet

Use it or lose it... The systems in our bodies are neural and physiological control systems, interconnected in a massive network. Systems that are not used, or systems that get too much help, can atrophy. We certainly want the neurons in Substantia Nigra to continue, or resume, creating dopamine at full capacity on demand. We do not want Sinemet to help the system with Levodopa more than absolutely necessary because we understand that this will create a damaging downward spiral this way:

More than enough Levodopa → less need for Substantia Nigra to secrete dopamine → Substantia Nigra atrophies → more need for Levodopa → Parkinson's Disease progresses with need for more and more Levodopa as the years go by.

A neurological disorder

Understanding of and research about Parkinson's leans on the science of neurology. To the best of my understanding, the field of neurology, just like the field of psychology I have observed for over 30 years, is lacking in fundamental insight and is seriously crippled. Elsevier just published an interdisciplinary handbook with a chapter by **Henry Yin, PhD, PI** titled **The Crisis in Neuroscience**. If you want to understand why the current sciences of psychology and neurology cannot begin to explain how we can walk and talk and chew gum at the same time, this, to me, is must reading.

Pain management

We want to satisfy Christine's need for pain relief and neural function while keeping Sinemet to a minimum. Pain is not the first thing that comes to mind when people think of Parkinson's. Christine experiences pain, and it turns out she is not alone, as discussed in **this article**.

Christine depends on Sinemet to keep pain at bay. The standard prescription is 2½ tablets, three times a day. This did not work for Christine, as Sinemet would be "used up" in several hours and pain return. We have worked out a schedule that works, spreading out the tablets, including a few sustained release tablets for sleep during the night, to 8 times a day. Christine's smartphone alarms make this possible. We will share our schedule on request.

We would love to find a way to reduce Sinemet naturally. This is where we pin our hopes on our low carb lifestyle, given that ketones are our brains' preferred food, ***not*** glucose. To the best of our understanding, ketones get around insulin resistance (we have both tested pre-diabetic in years past) and provide a full measure of preferred fuel to Substantia Nigra neurons, including the mitochondria that reside within them.

Support

Christine benefits from supportive physicians at Kaiser Permanente.

We participate in support groups, both for Parkinson's patients and for care givers.

We benefit from an outstanding outreach program at **Stanford**, where staffers keep us abreast of developments in the Parkinson's world—books, lectures, webinars and podcasts.

We make friends with support organizers as well as other patients and care givers.

In conclusion — some of what we think we understand

Understanding evolves. Our understanding determines what we want and what we do. We appreciate assistance to correct, clarify, expand, and validate our understanding.

- **Parkinson's**
  Parkinson's Disease is an amorphous collection of symptoms, impossible to pin down, with neural malfunction the common denominator.
- **Exercise**
  Experience shows that vigorous exercise slows progression of this degenerative disease.
- **Medication**
  Sinemet, i.e. Levodopa/Carbidopa is the preferred medication. Many other medications are available, with varying efficacy and side effects. As always, we prefer to keep medication at a minimum.
- **Nutrition**
  We see indications that an ample supply of ketones in our blood stream will keep our neurons well fed and fully functioning. It appears they will regenerate too.
- **Keto — Low carb, high fat, adequate protein**
  Despite a history going back long before the advent of agriculture, better than 100 years of medical research, and an explosion of research in the last 25 years, the idea of employing a low carb lifestyle as treatment for medical problems is nowhere near recognition/acceptance/inclusion as evidence-based medicine.

  Specifically, the idea of employing a low carb lifestyle as treatment for Parkinson's disease is not yet seriously considered by experts. We find compelling evidence that it will help us.
- **Brain health**
  We understand that continuing a low carb, high fat, adequate protein lifestyle with plenty of exercise is the best we can possibly do for our health and mental fitness. This will slow down or even reverse the progression of Parkinson's disease.

Looking to the future

Christine and I look to the future with confidence. Life is good! We appreciate support from family and friends. We trust that our basic good health, a result of Christine's vigilant commitment to healthy living all along, will support us going forward. We realize that it is up to us to learn how to improve and maintain our health for the duration. We are committed to vigorous exercise to keep our minds and bodies in shape. And we are happy to perform what may be called anecdotal research regarding the efficacy of a low carb, high fat, adequate protein, ketogenic lifestyle to help us stay healthy and keep our brains and the rest of our nervous systems in good shape. Time will tell.

Downloading

Downloading Sofia's exercise videos

There are lots of computer programs available to download video, so the one I have used for years is just one of many. I'll tell you about *Replay Media Catcher (RMC)* from Applian Technologies, available for Mac and Windows with extensive tutorials. I note that when I right click on the video program icon (using Google Chrome) I can copy the link address, then paste it in RMC. For these videos, file names repeated, so I copied and pasted four links, one after the other, forming a group, starting with March 14, then inserted numbers before the file names while I still could see which was which, so March 14 is "01 Rörlighet.mp4" (01 Flexibility.mp4), and May 1 is "30 Träna med ryggsäck.mp4" (30 Train with back pack.mp4). By moving the downloaded files to another folder with a file manager, I could delete the file names form the RMC window without actually deleting the files, because the entry in the RMC window no longer pointed to them.

Downloading from YouTube

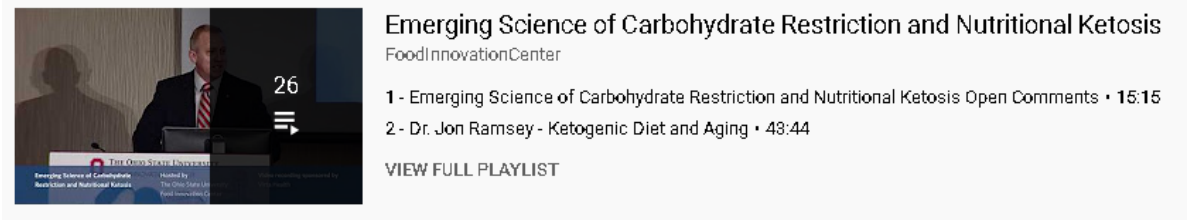
I have found and downloaded exercise videos from YouTube as well. I did not have much luck until a friend suggested I use words like "Exercise at home for seniors". Most of what I found seem amateurish compared to Sofia.

Downloading playlists from YouTube

Search YouTube for videos of your choice—exercise or presentations.

Here, we search for *Emerging Science of Carbohydrate Restriction and Nutritional Ketosis*.

YouTube displays:



https://tinyurl.com/ketoconference Link added April 2024

Note "26" in the thumbnail image. If you click on VIEW FULL PLAYLIST, YouTube will display all 26 presentation thumbnails and titles. When I moved my cursor over the image, it displayed PLAY ALL, but I found that if I right-click, I saw a menu where I could select "Copy Link Address". So I went directly to the top window in RMC and pasted it, then hit ENTER. RMC went to work, downloading all 26 videos while I waited, perhaps half an hour.

Page	Link in text	Internet
1, 3	Holiday Report	http://www.forssell.com/HolidayReport.pdf
1, 4	StudyKetoParkinsons.pdf	http://www.forssell.com/StudyKetoParkinsons.pdf
1	bedroom gym	http://www.forssell.com/HomeGym.pdf
2	Avenidas	https://www.avenidas.org/programs/health-wellness/
2	Jenni Castaldo	https://www.yelp.com/biz/jennis-health-and-fitness-menlo-park
2	Senior Center	http://www.adaptivepevmsc.org/
2	Theresa Najjar, PT, DPT, MS	https://synapticpt.com/about/meet-theresa/
2	story HERE	https://www.vk.se/2019-10-11/sa-hamnade-idrottslararen-fran-umea-i-svts-program
2	long INTERVIEW	http://umepodden.podbean.com/?s=Sofia
2	videos on YouTube.	https://www.youtube.com/playlist?list=PLqM51Sy0e1R1EjrVa_sD6AuUNPLg0TfpI
3	CDC	https://www.cdc.gov/diabetes/library/features/truth-about-prediabetes.html
6	review	https://meridian.allenpress.com/mhc/article/2/2/25/36885/Parkinson-disease-A-summary-of-recent-evidence
6	Small Vessel Disease	https://betterhealthwhileaging.net/cerebral-small-vessel-disease/
6	Sinemet	https://en.wikipedia.org/wiki/Carbidopa/levodopa
7	Levodopa	https://en.wikipedia.org/wiki/L-DOPA
7	Sinemet pills	http://parkinsonquebec.ca/wp-content/uploads/2015/07/levedopa.pdf
7	blog article	https://www.psychologytoday.com/us/blog/diagnosis-diet/201906/parkinsons-alzheimers-and-the-new-science-hope
7	Dr. Georgia Ede	https://www.diagnosisdiet.com/about
7	Sinemet pills	http://parkinsonquebec.ca/wp-content/uploads/2015/07/levedopa.pdf
7	control systems	http://www.livingcontrolsystems.com/download/pct_readings_ebook_2016.pdf
7	massive network	https://www.psychologytoday.com/us/blog/in-control/201910/you-have-control
8	Henry Yin, PhD, PI	https://www.neuro.duke.edu/people/faculty/henry-yin#block-views-publications-block
8	The Crisis in Neuroscience	https://www.sciencedirect.com/science/article/pii/B9780128189481000034
8	this article	https://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed/Does-Parkinsons-Hurt
8	Stanford	http://parkinsons.stanford.edu/

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