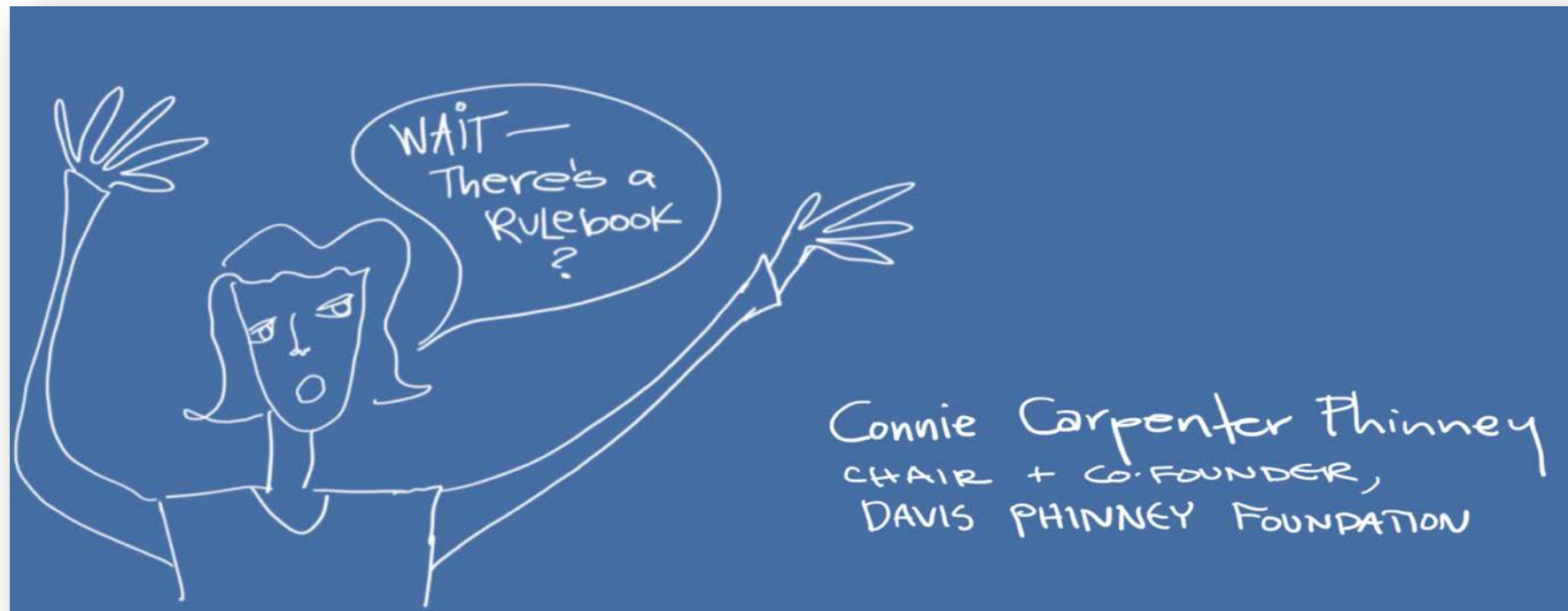


Care Partners. Rewriting your Rulebook.





About me.

My mom had MS.

I was 5 when she was diagnosed.

My husband has PD.

He was 40. Our kids were 6 +10.

That was in 2000.

I am an incurable optimist.

I believe in cultivating happiness.

And keeping my halo untarnished.

Husband, Wife, Brother, Sister, Daughter, Son, Friend, Partner, Mother,
Father, Medical practitioner, Family, Caregiver

You

Husband, Wife, Brother, Sister, Daughter, Son, Friend, Partner, Mother,
Father, Medical practitioner, Family, Caregiver

WHAT I KNOW



You didn't ask for this.
Neither did your PWP

You are not alone.
But you may feel that way.

It's okay to dislike Parkinson's.
Avoid disliking your PWP.

You can do this!
Though you think – at times that you can't.

WHAT WE KNOW ABOUT PARKINSON'S

- It's 24/7
- It can turn your world upside down
- It involves daily concessions
- It's isolating
- It rarely *plays nice*
- It's unpredictable + complicated
- Tremor is the tip of the iceberg
- Non-motor symptoms are confusing + confounding
- We don't have a road map or GPS to guide us.



RULEBOOK

1. Reboot. Rewrite.
2. SAFETY FIRST
3. INFORMATION is power.
4. MEDICINES
5. DOCTOR VISITS
6. SUPPORT
7. CHALLENGE
+ EMPOWER



1. REBOOT + REWRITE

- The Rulebook must be dynamic, and will evolve over time.
- The Rulebook is a guideline for **optimal health, safety and well-being**
- The Rulebook is rooted in knowledge, relies on good manners and yet, demands respect.
- The Rulebook gives you the chance to reset*, assess, reorganize, and rebuild.
- The Rulebook will help you to avoid unproductive emotions like anger or guilt

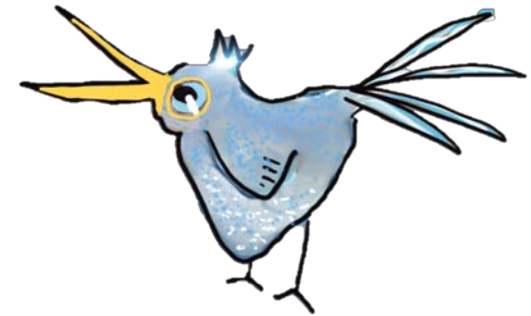
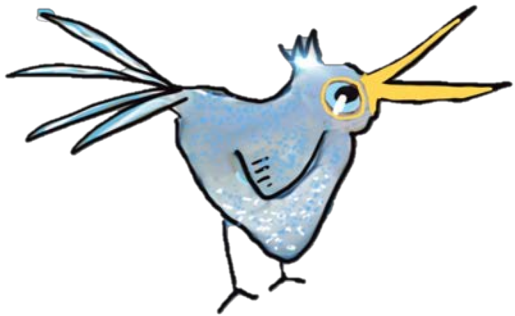
*we can all use a do-over, right?

2. SAFETY FIRST

- Declutter (visually and physically)
- Remove tripping hazards (like area rugs)
- Minimize “fall” risks (like extension cords)
 - No Ladders. Ever.
- Maximize supports like grab bars
- Cane- for travel + early boarding
- Sleep safe
 - Nightstands? Separate beds?
- Driving? Get tested
 - Disabled parking pass
 - (your PWP needs the extra space)

3. INFORMATION IS POWER

- Please sign up for our EVC manual -
It's Free!
- Join or start a study group
- Ask Questions + Seek Answers
- Be smart when considering the source
of your information.



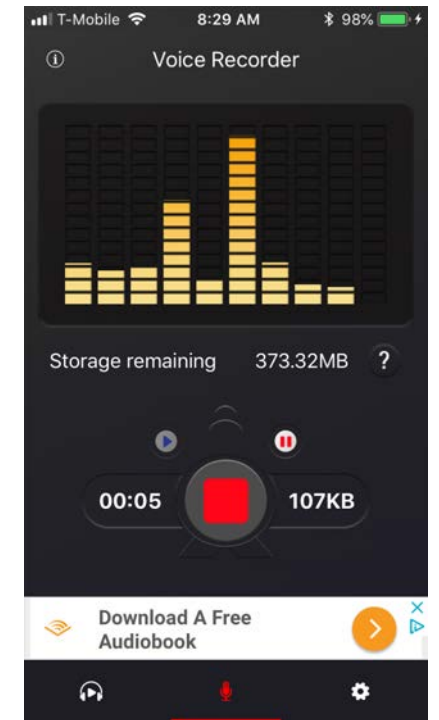
4. MEDICINES

- ① SIDE Effects
- ② DOSAGE + TIMING
- ③ UNDERSTANDING ON/OFF



5. DOCTOR VISITS

- NEVER let your PWP go to any doctor appointment alone.
- RECORD the conversation
- SEE a Movement Disorder Specialist at least once/year
- Get a signed HIPAA release from your PWP for each of your medical caregivers
- Get all of your PWP's legal docs in order



Download a recording App for your phone
– don't forget to save the file!

6. SUPPORT

- Build your care team:
Family, Friend(s), Medical practitioners, PwP
- Disability ?
- Financial planning + legal directives
Are all your ducks in a row...?



7. CHALLENGE + EMPOWER

- Task your PwP
- Enable your support team
- Disable fear
- Seek contentment
- Choose to be – or stay – positive
- Exercise!



The road is long.....



Please take care... of you.