8 items we learned from Jackie's PSP Journey

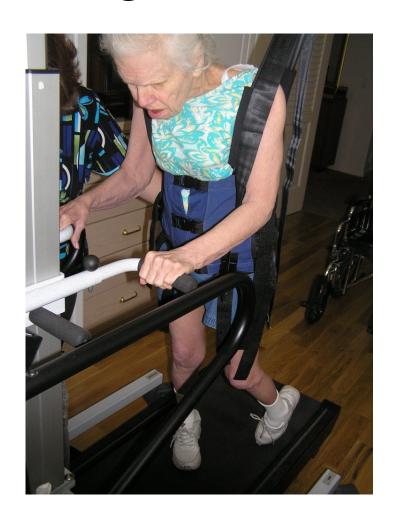


- 1. Get <u>second</u> (or third) <u>opinions early</u>, especially for unexplained symptoms.
- 2. <u>Don't accept an unconfirmed or</u>
 <u>non-specific diagnosis</u>. Push to get
 to a top neurologist preferably a
 Movement Disorder Specialist
 (MDS).

- 3. Make the significant care decisions early
 - a. Feeding tubes
 - b. Do Not Resuscitate (DNR) orders
 - c. Hospitalization or die at home
 - d. Brain donation

Use an Advanced Health Care Directive and Physician's Orders for Life-Sustaining Treatment (POLST)

4. Start exercise early and continue exercise as long and as much as possible

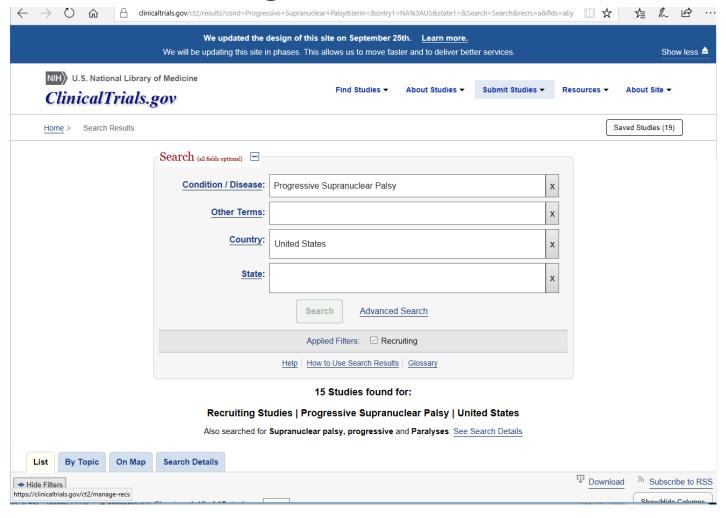


5. Make life as normal as possible.



6. Check out available clinical trials.

www.clinicaltrials.gov



- 7. As the caregiver or patient, <u>be</u> <u>proactive</u>,
 - a. participate in support groups,
 - b. go to presentations on the disease and
 - c. research on-line.

Attitude

- 8. <u>Keep a "Binder"</u>
 - a. Cross doctor communication
 - b. Researchers

Summary

- 1. Second (or third) opinions early
- Don't accept an unconfirmed or non-specific diagnosis
- 3. Make the significant care decisions early
- 4. Exercise as long and as much as possible
- 5. Make life as normal as possible
- 6. Investigate Clinical trials
- 7. Be proactive
- 8. Keep a "Binder"

