THREE THINGS I LEARNED AS A CAREGIVER
December 2, 2023
Discussion Co-hosts: Brain Support Network (BSN) and Stanford Parkinson's Community Outreach
Participants: Local BSN and Stanford caregiver support group members

Recording of the discussion:
https://youtu.be/3Ld8-Wzek_o

Blog post with a summary of the discussion (by Jordan Dagan):
https://www.brainsupportnetwork.org/top-3-things-learned-as-caregiver-recording-dicussion-summary-notes/

#1 - JOHN

3 Things I learned while experiencing the challenge of dementia caregiving: The very first thing that came to mind is, 'Slow Down'. Having said that:

#1- Believe your eyes. You will learn that everyone is 'behind the curve' when first seeing the symptoms of this malady. You are the only one with the whole picture. The person being afflicted is in personal denial, not believing, then hiding incidents from loved-ones as they occur making recognition difficult. Unusual acts/faux pas will happen that are hard to understand & difficult to explain to others [including medical personnel]. Recognize subtle lifestyle changes.

#2 Every case is different. I do not mean clinically as much as practically. There are differences as to the patient/caregiver dynamic. Is the patient a parent/spouse/sibling, gender, age? (If it's your parent, that might be more "natural" as we may've seen our parents taking care of grandparents. A spouse is a whole different story.) Each combination has its own issues and concerns.

#3- Be conscious of subtle stressors. Remember, YOU are needed! You can not break down. Don't forget to take care of yourself. Beyond the obvious, you are dealing with many underlying stressors/changes in your life. Big-picture life plans/expectations. Life-style changes- at first subtle but growing. Relationship- long established responsibilities change. Your own UNIQUE changes. You will need assistance (sooner than you think)

All to say- SLOW DOWN

#2 - DOUG

1. Figure out who is your (caregiver) backup in case you predecease your caregiver. Create a plan or set of directions in case something happens to you. Next of kin or trustee needs clear instructions on what to do in case you are incapacitated or die, including what to do right away. Share account info and passwords.

2. Create a budget. Having a patient with one of these diseases can add $50k - $100k per year or more, even with insurance. How will this be handled?

Later…

3. Check for clinical trials – as soon as you can. The better shape the patient is, the better the chance for acceptance and success in the trial.

4. Explore caregiving alternatives sooner than later including possible homes. Some places won't take PSP patients; it’s good to know this ahead of time.

5. Plan ahead.

6. Come up with a plan for how you will have some free time to do pleasurable things. Full time caregiving can be a huge drain. Getting free time is very difficult.

7. By the time you realize you need a U-Step walker, special wheelchair, or chair lift, it could be weeks/months before you get it. Also by the time we got a great wheelchair, Diane didn't need it because she was bedbound. Also how is the patient going to be transported as the disease progresses. Plan ahead for things you may need, such as chair lifts. Medicare will pay for a UStep walker ($600) but if you’ve already used your “walker money” on a rollator walker, you are stuck.

Later….

8. Handicapped bathrooms: pushing UCSF to add commode chairs available.

9. Legacy video: Life before PSP, life after PSP, message to the family. Offered by Sutter Palliative Care.

#3 - JANE

Not just the person with PD, the disease involves both the PD person and the caregiver. Work as a team as much as you both can.

Lack of support around emotional/psychological impacts offered by the medical infrastructure. Extra important to have therapy to navigate the changing relationship.

[Denise: Stanford Parkinson’s has a list of therapists in the local community with experience treating families coping with PD. See:
https://med.stanford.edu/parkinsons/northern-california-resources/sw.html]

Re: medical equipment. Adult day centers often have medical equipment repositories that people have donated. Walkers, wheelchairs, canes, etc. Senior centers and centers for the disabled (in each county) have loan closets for equipment.

Later…
Adult day care centers can be wonderful opportunities for both client and family.

#4 - CANDY

1. You will make mistakes and you will feel guilt after your loved one dies. Try to understand that hindsight is always 20/20.

2. If you have young children talk to them sooner rather than later about their loved one's disease. It was tough for my late husband and me to talk to our young kids about his MSA diagnosis. Get professional help to do it if you need to.

3. Take care of yourself and be aware of your own body. In our MSA support group, we had several women who had health issues after their spouses passed. Breast cancer, stroke, and debilitating back injury were a few of the issues that occurred.

#5 - ROBIN

(I tried to think of things that I don’t believe others will mention)

1. At some point, the caregiver needs to change his/her HCPOA document such that the spouse with a neurological disorder is NOT the caregiver’s healthcare proxy, especially in the case that the spouse has dementia.

2. If an adult child is the HCPOA and has financial POA access to a parent’s bank account, know that this financial POA relationship ends on the death of the parent such that the adult child can no longer gain account access. The best work-around is that the parent has a trust, the bank account be a trust account, and that the adult child is a named trustee.

3. If you have a credit card on the same account as your spouse, be sure you have a credit card where you (the caregiver) are the primary cardholder. Many women have joint credit card accounts with husbands, where the husband is the primary cardholder and the wife is an authorized user. Once the credit card issuer learns that the primary cardholder has died, the

card will be canceled. The authorized user can apply for a new credit card, often with a much lower credit limit.

Later….
4. Category - profound (to me) things I've heard. We all want to be remembered. When you are visiting a dying person, say that you will remember them.

5. Category - profound (to me) things I've learned. We all want to be useful. Find things the care recipient can do to make the care recipient feel useful.

#6 - DENISE contributing for husband MARC (not present)

Low blood pressure upon standing or after a large meal can be scary when your loved one faints or becomes catatonic. Don't panic but remember that lightheadedness can lead to falls, so seek a neurologist's advice asap. Falling can lead to catastrophe. Marc's Dad fell while getting out of bed during the night and broke his neck falling onto a hardwood floor. He could not swallow his meds after a halo was surgically applied to brace his neck and died shortly thereafter.

A mindfulness teacher once told me that the best gift you can give the person you're caring for is to do things at their speed. Mindfulness can be an invaluable tool to achieve this.

#7 - ALISON (not present)

My advice (if it's helpful to others) is not to assume that all congregate care is bad, or that your loved one will be less happy there. I agonized over the decision - the anguish was wasted, as my brother escaped his terrors and anxieties completely as soon as he moved into a locked setting—turns out the 'bad guys' cannot get IN, which made him feel super-safe! No more delusions, nightmares, paranoia—nearly overnight he could tell he was safe, and that has made a world of difference. He gets everything he needs under one roof—excellent PT, his haircut, podiatrist, etc.—along with professional caregivers that have allowed me to get back to being a loving sister. Stereotypes aren't always helpful!

#8 - DAG (not present)

"The Five Regrets of the Dying" by Bronnie Ware.

#9 - MEL (not present)

1. Don't be a hostage to circumstance. Find any/all ways to stay connected to the outside world.

2. Look ahead...WAY ahead...and plan to the extent possible: ie, scout out memory care facilities, daycare centers, respite care, in-home care, ALL OF IT.

3. Feel and express that rage safely.

4. Find that caregiver friend with whom you can be completely honest.

Later…
5. When friends ask yet AGAIN about LBD (CBD, MSA or PSP) tell them to google the disease. You're done. Also, when friends ask, 'how is he/she doing?' I just say, 'SAME.' I deflect all idiotic questions that I've answered any number of times. Attempt to TEACH/inform your friends about all that has been written lately about how people process grief. EDUCATE!!!

6. DRUGS DON'T WORK...for long anyway. Treat whatever obvious symptoms present: anxiety, sleeplessness, pain. But forget the cognitive/memory stuff. Not worth it. Also, blood pressure and cholesterol meds are likely unnecessary at this point.

[Candy: depends on your disease!]

7. Make as much peace as you are able with the concept of 'forever incurable.' There will be plateaus, but the progression is downward.

8. If a loved one is being mean, TELL THEM.

9. Expect that some of those closest to you will never understand or simply not show up. FIND NEW FRIENDS.

10. Be the one in charge. These decisions are impossible. There will always be someone who doesn't agree. Drag uninvolved family kicking and screaming into the light. No one gets a pass. There's strength and power in anger, but DO NOT ACT LIKE A VICTIM. No one likes a victim who is always baiting for support. Stay tough. You can do this.

11. DO NOT COMPARE YOURSELF TO OTHER CAREGIVERS. There will always be someone who is as faithful, caring and loving as a lap dog. Then...there's me. Yes, I promised in sickness/health; but there are limits. Everyone has limits.

#10 - JUDITH (not present)

Don’t move to a rural area where good-quality healthcare is far away and there are no caregivers to be hired. Isolation is a terrible thing for both the patient and the caregiver.

#11 - LAURIE (not present)

1) Try your hardest to get your cared one to do physical exercise. Be creative if the usual doesn't work (i.e. get them a personal trainer at the gym, sign them up for boxing, get them a special bike). Whatever works! I strongly believe that exercise slows down the progression of this disease and keeps people out of wheelchairs much longer! AND THAT GOES FOR THE CAREGIVER AS WELL!

2) As this disease progresses, it becomes more work to get your cared one out, and sometimes it's tempting to say, "Forget it!" Search out venues that are accommodating so there is less stress (i.e. the Bing Concert Hall at Stanford has gender neutral bathrooms and good handicapped seating; most museums have wheelchairs for loan (if your cared one gets too tired with a walker) and gender neutral bathrooms, etc.)

3) Invite your good friends over to your house for dinner, lunch, or whatever!! It is stimulating for your cared one, and it keeps you from becoming isolated. If they are good friends, they will hang.

#12 - LYN (not present)

My #1 tip is to attend caregiver-only support group meetings, and establish relationships with caregivers outside of the meetings.

Find something you love to do that re-charges the batteries, and keep doing it.

Work with a physical therapist and your family member to learn how to fall and how to get up after a fall.

#13 - MICHELLE (not present)

Be smart about equipment. When my husband was diagnosed with MSA eight years ago at age 52, we didn’t know what we didn’t know about equipment that makes the MSA journey easier. Since then, we have rented and purchased equipment that has been essential for helping improve my husband’s quality of life and my experience as a caregiver. Two common challenges we have utilized equipment for are pressure sores and safe transfers. Unfortunately, the only equipment Medicare covers for safe transfers is a Hoyer lift, which has its purpose but may not be the best solution for individuals who can bear weight and do not have severe hypotension upon standing. For these individuals, equipment that enables them to safely transfer while not being completely immobilized is a better solution for their health and well-being according to medical professionals. Currently, we use a sit-to-stand lift. It's great for my husband, and it's easy to use for caregivers. (A word of caution: Not all sit-to-stand lifts raise an individual to a standing position and/or fit through narrow bathroom doors.) Consider equipment from the vantage point of the present and the future. Some equipment is covered by Medicare. To get this equipment, follow your health plan's instructions. For non-Medicare covered equipment, shop around. If you don't have Medicare, check your health plan's Evidence of Coverage for durable medical equipment (DME) covered by the plan.

#14 - DIANNE (not present for items 1-3)

1- getting care help early but framed as friend helping caregiver.

2- be prepared with all finances!!! with passwords access!!!!

3- adult day care classes

Later:
4- Medical equipment loan program, San Carlos. Accept medical equipment on Wed afternoons in San Carlos; clean it and repair it if needed. Loan it as needed, on Saturday mornings. Free. Lots of the equipment is brand new. 650-590-9112, freemedequip.org

#15 - TIM

"Getting yourself out of the way" in caring for another. Caregivers are feeling distressed about their loved one's medical status. Caregivers need to get out of the way with their feelings! Sometimes touching can be repetitive such that it can turn into an annoyance. Touching isn't mandatory. If you are visiting someone for the first time after a decline, let yourself go to be present with the other.

#16 - RANDI

1. Ask for help! Be specific.

2. If things are causing anxiety, let it go.

3. Be very careful in taking your loved one traveling. It can be disorienting to your loved one.

4. Medication: You know your loved one the best.

#17 - NANCY

Buy a walker at Walmart

#18 - BHUSHAN

Crowded and noisy places can be overwhelming for those with LBD, PD, etc. Heat and cold, light and noise, strong smells, may be overwhelming. Treadmill exercise at home can offer a controlled environment.

#19 - DENISE

A mindfulness meditation teacher once told me to do caregiving at the same speed as the care recipient can handle! Do things at the speed of the care recipient. This makes them not feel like they are not a burden.

#20 - SUSAN

Story of our local support group member who is creating a book of photographs (she takes) and commentary (provided by her husband).

#21 - TIM

Invited kids to do stories of his wife and himself. One excuse to do this now is that her voice is going.

#22 - DENISE

You may not be able to rely on rest areas, when traveling. If you need a break from driving, consider stopping at Costco for cheap gas, and visiting the restroom and cafe. Lowe's is also good for this, since the bathrooms are located in the front of the store.

#23 - JANE

Slowing down is difficult. Biopsychosocial medicine: if he feels like he's rushing (ex. waiting for the elevator), take an opportunity to breathe.

#24 - JOHN

Make the most of having to wait

#25 - DIANNE

Take a walker into the toilet stall. Grab bars are too far away.

#26 - CANDY

Get palliative care or hospice care involved earlier, rather than later.

This file is at this link:
https://docs.google.com/document/d/1hhtTjNDujYvmgwqPUmJ9kdIKB-XxPSvyt4pe4270Y2Y/edit?usp=sharing