

# Caregiver/Partner Needs

“Caregiving Calls Us to Lean into Love & Strength We Did Not Think Possible” ~T. Walker

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# Caregiver vs. Care partner ?

- Informal Caregiver/care partner – are unpaid volunteers who offer service medical assistance or assistance with tasks of daily living ( can be spouse, friend, family member...)
- Formal caregivers – paid providers who give care or assistance at home or care setting such as NH, assisted living, day care etc.

# (My) Care Journey

- Everyone is different – with unique challenges and some common issues as well
- May begin as partners but all eventually become caregivers!
- Caregivers are the hidden figures – often seen but rarely heard- with everyone focusing on the patient is easy to become invisible!

# Who are the caregivers in this country?

- ~43 million Americans have provided un- paid care to an adult or child in the last year
- ~32 million Americans have given care to someone over 50 in the last 12 months
- >75% of all caregivers are female & spend more than 50% of time providing care compared to men

# Demographics & Statistics

## ○ Women make up the majority of caregivers

1. 75% of all unpaid caregiving
2. Do 4x the hours than men on average 22hrs a week
3. 65% of care recipients are female w/ average age of 69

## ○ Male Caregivers

1. Male caregivers are less likely to provide personal care; only 16% of men help with bathing compared to more than 30% of women
2. 40% of male caregivers use paid services to help with loved ones personal needs

# Gender differences in Caregiving/ Needs

## Men

- Hands off
- Less defined support group
- Not used to multi-tasking / running a household
- More financial resources
- Pay for help
- Get angry /frustrated more

## Women

- Hands on
- Better support system
- Able to multi-task
- Less financial resources
- Get depressed & overwhelmed

# Making it work...

- Life does NOT stop because of Parkinson's Disease: we must learn to find a Balance
- Know your limitations
- There are many seasons in life/disease

# Making it Work...

- Open communication-

1. What are the patient's wishes & caregivers wishes- are they feasible?
2. Make short & long term plans
3. Make wills/power of attorney
4. Financial Planning
5. End of life choices- hospice/NH etc.
6. Make sure caregiver knows where everything is e.g. marriage license, bank accounts, phone numbers etc.
7. May have to get job or go back to school/early retirement/change of career to stay home
8. Long term care insurance



# Making it work..

- Get/find support

PD community, church, friends,  
family .....can't go at it alone- have a list ready  
of things you need help so if someone asks e.g. pick  
up groceries, take to doctor, pick up dry cleaning

- Be open to new technologies that can help you  
care for your loved one/also includes treatments

# Resources for caregivers:

- Doctors/Counselors
- Religious groups
- Social workers
- National/ local organizations Parkinson's / caregiving such as Neuro Challenge, Parkinson's Foundation
- Meals on wheels
- Nurses aids to help bath etc..
- Sitters – can be found cheaper at nursing schools, social work schools..
- Respite care services

# Making it work...

- Take care of yourself –
- airlines always recommend putting your oxygen first BEFORE assisting anyone else!!! – Not selfish means your needs are important as well..

# Making it work...

- Find time together & alone
  1. Let patient do for him/herself while early stages

# Take Breaks

- –Burn & Crash fast; your loved one will suffer if you are no longer able to care..
- Watch out for depression/  
irritability/anger/
- frustration

# Allow yourself & your partner time to COPE

Time to cope to NEW NORMAL (ever changing)

Time to grieve

Time for spouse to grieve/cope

Time for socialization

Time for talk therapy, art therapy

Important to remember everyone grieves and process info at different pace..

Chinese Bamboo Tree- takes 5 years to grow- it requires constant care most of 5 years without much growth ONLY to grow 15ft in 5 weeks!

# Avoid Confrontations

- #1 neither one will be comfortable all the time- give-take relationship
- #2 decide on a philosophy to tackle illness – common goal
- #3 there can only be 1 driver at a time

“Too many cooks spoil the broth”

- Don't sweat the small stuff
- Concentrate on the love/  
the positive



This too shall pass!

- Make most of your time together & enjoy Life-  
after they are gone is  
the memories that  
remain...

Only after you allow yourself to grieve can you laugh again...



Unknown and often unnoticed, you are a hero  
nonetheless.

Your love is GOD at is BEST.

You walk by faith in the darkness of the great  
unknown,  
and your bravery, even in weakness, gives life to your  
beloved.

You hold their shaking hands and provide the ultimate  
care;

With your mere presence you provide immeasurable  
comfort  
and courageously face the giant of PD and its  
despair.

It is your finest hour, although you might be unaware.

You are resilient and beauty excelled;

You are the caregiver and have been blessed for  
simply being there.

# References:

- Caregiver statistics: Demographics/family Caregiver alliance [www.caregiver.org/caregiver-statistics-demographics](http://www.caregiver.org/caregiver-statistics-demographics)
- Caregiving2015 [www.caregiving.org/caregiving2015](http://www.caregiving.org/caregiving2015)
- Facts about caregivers in the US [www.hopegrows.net/news/facts-caregivers-in-the-United-States](http://www.hopegrows.net/news/facts-caregivers-in-the-United-States)