

Parkinson's & Lewy Body Dementia Caregivers: What do we know & what can we do?

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Excellence

**Davis Phinney Foundation Victory Summit – Green Bay, WI
October 11, 2024**

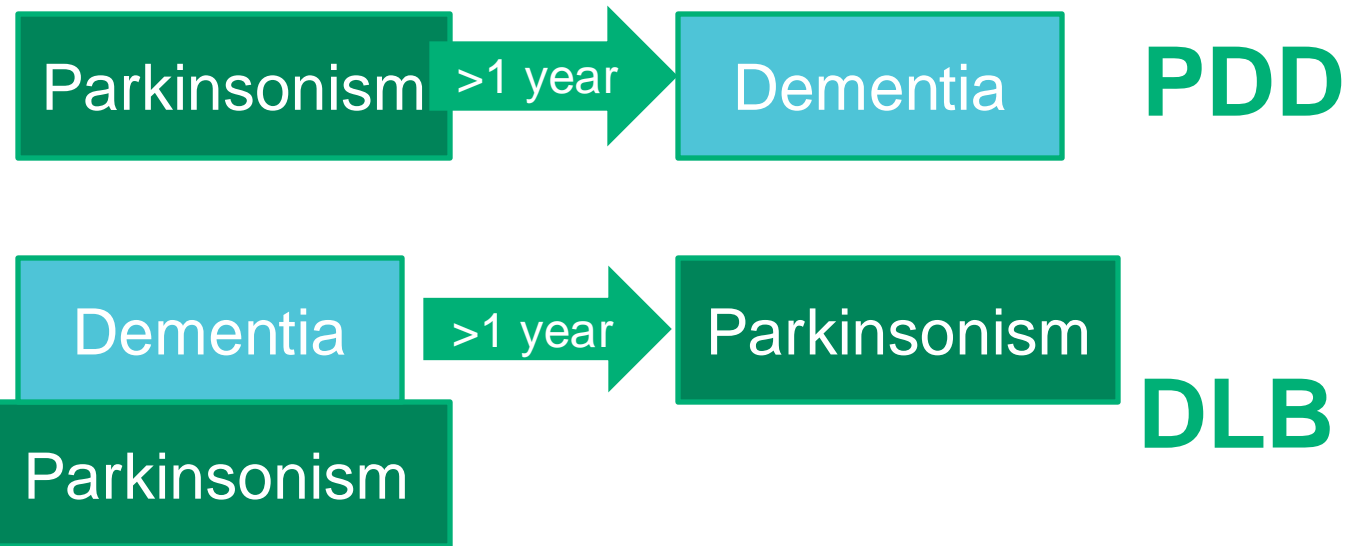


On the Horizon

- What do we know about Parkinson's & Lewy Body Dementia caregivers?
- What can we do to support caregivers and those they love?



PDD, DLB, LBD: A Tale of Semantic Confusion



The (in)evitable triggers for hospitalization and death

- **Leading causes of hospitalization:**

- Falls
- Urinary incontinence or infection
- Dehydration \pm metabolic derangements
- Neuropsychiatric issues: hallucinations, delusions, agitation, depression, anxiety, dementia
- **Caregiver strain**

- Once hospitalized, individuals with Parkinson's and with Lewy Body Dementia have longer hospitalizations, more complications, and are more likely to be discharged to a nursing home

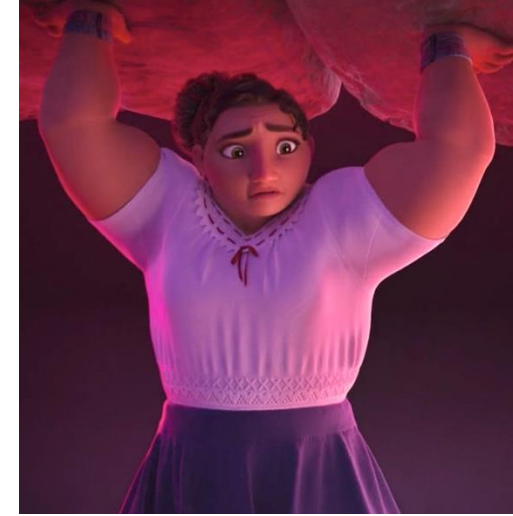
- ***Hypothesis: Many are preventable or manageable at home, if recognized early***

- **Doing so requires an educated, engaged, observant caregiver**

What do we know about Parkinson's & LBD caregivers?



Parkinson's & LBD Caregivers: Overburdened, understudied



- >83% of community-dwelling people with PD or LBD rely on unpaid caregiving from family members → **18.5 billion hours of care valued at \$232 billion**
- Nearly twofold loss of direct income among caregivers in 5 years
- PD/LBD family caregivers have higher caregiver strain, burden, and depression than caregivers of people with Alzheimer's Disease and related dementias
 - Combined deterioration in motor, cognitive, neuropsychiatric, and non-motor domains, plus unpredictability, motor & cognitive fluctuations

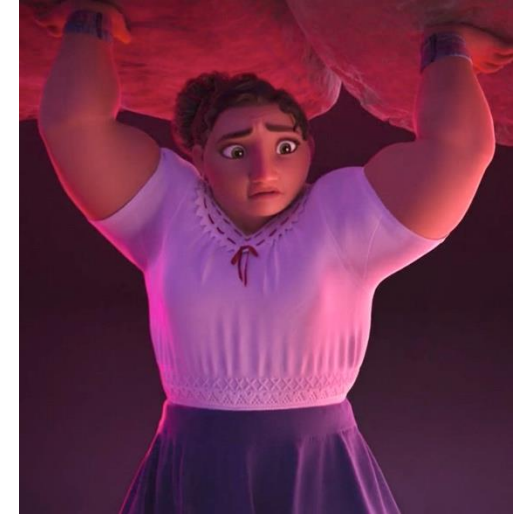
Prevalence of Comorbidities Among Current Lewy Body Dementia Caregivers, by Age Group

Comorbidity	All	Age 18-44	Age 45-54	Age 55-64	Age 65-74	Age 75-84	Age 85+
Prevalence Among	(n=182)	(n=11)	(n=11)	(n=48)	(n=70)	(n=38)	(n=4)
Current Caregivers,							
n (%)							
High blood pressure	70 (38.5)	1 (9.1)	4 (36.4)	15 (31.3)	29 (41.4)	18 (47.4)	4 (36.4)
Depression	68 (37.4)	5 (45.5)	6 (54.5)	21 (43.8)	28 (40.0)	7 (18.4)	1 (25.0)
Back pain	68 (37.4)	5 (45.5)	5 (45.5)	15 (31.3)	27 (38.6)	13 (34.2)	3 (75.0)
Other medical problems	56 (30.8)	4 (36.4)	3 (27.3)	16 (33.3)	19 (27.1)	12 (31.6)	2 (50.0)
Osteoarthritis or degenerative arthritis	53 (29.1)	2 (18.2)	2 (18.2)	13 (27.1)	17 (24.3)	17 (44.7)	2 (50.0)
Heart disease	24 (13.2)	0	0	4 (8.3)	17 (24.3)	7 (22.6)	1 (25.0)
Constipation	24 (13.2)	2 (18.2)	2 (18.2)	5 (10.4)	12 (17.1)	2 (5.3)	1 (25.0)
Diabetes	16 (8.8)	0	0	8 (16.7)	5 (7.1)	2 (5.3)	1 (25.0)
Ulcer or stomach disease	16 (8.8)	0	0	5 (10.4)	7 (10.0)	3 (7.9)	1 (25.0)
Rheumatoid arthritis	15 (8.2)	0	0	3 (6.3)	8 (11.4)	3 (7.9)	1 (25.0)

Parkinson's & LBD Caregivers: Overburdened, understudied

- **Caregiver strain independently increases person's risk of hospitalization & nursing home placement**
- No effective PD or LBD caregiver interventions to date
- Among dementia caregiver interventions, only costly, multimodal approaches demonstrate benefit
- **Paid caregivers:**
 - Not covered by insurance, including Medicare or hospice
 - Extremely expensive (~\$US 30+/hour, or ~\$5,000/week)
 - High demand, low supply
 - High turnover & burnout pre-COVID, worse post-COVID
 - Minimal to no training in dementia, PD, end-of-life care

...not a sustainable option for most



What can we do
to support
caregivers
and those they love?





Strain is high among caregivers of homebound individuals with advanced Parkinson's and Lewy Body Dementia

NYC-based Home Visit Pilot Study:

- Despite advanced disease, individuals receiving home visits did **not** demonstrate expected decline in quality of life
- Among 10 advanced PD caregivers completing MCSI at baseline & one year, strain increased from mild to moderate (17.1 to 23.2, $p = 0.04$)
- Among 3 who withdrew, median V1 baseline was 42 (range 29-55) suggesting severe strain
- **Conclusion: home visits may help patients but aren't enough to mitigate caregiver strain**

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Interdisciplinary Home Visits for Individuals with Advanced Parkinson's Disease and Related Disorders

Jori Fleisher, MD, MSCE^{1,2}, William Barbosa, BS², Meghan M. Sweeney, LCSW³, Sarah E. Oyler, BSN, RN⁴, Amy C. Lemen, MA, LCSW², Arash Fazl, MD, PhD², Mia Ko, DO⁵, Talia Meisel, BS⁶, Naomi Friede, BA², Geraldine Dacpano, MPH², Rebecca M. Gilbert, MD, PhD², Alessandro Di Rocco, MD², and Joshua Chodosh, MD, MSHS^{7,8}

RESEARCH

Disease severity and quality of life in homebound people with advanced Parkinson disease

A pilot study

Jori E. Fleisher, MD, MSCE, Meghan M. Sweeney, LCSW, Sarah Oyler, RN, Talia Meisel, BS, Naomi Friede, BA, Alessandro Di Rocco, MD, and Joshua Chodosh, MD, MSHS

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Could connecting caregivers together,
one-on-one, ease the journey and
isolation?





Peer mentoring in other conditions

- **Initially in Alzheimer's Disease caregivers:**
 - Former caregivers paired with current caregivers, mixed quantitative results, strong qualitative data supporting benefits for mentors & mentees
- **Peer mentoring has subsequently led to improved outcomes among:**
 - Trauma survivors
 - Individuals with kidney disease
 - Sedentary older adults
 - Young adults with neurologic disorders
 - Family caregivers of people with cancer
 - Bereaved parents of children who died from cancer

Charlesworth G et al, 2016; Charlesworth G et al, 2017; Greenwood N and Habibi R, 2014; Walshe C et al, 2020; Zwaima A et al, 2022; Perry E et al, 2003; Stevens Z et al, 2015; McKenzie G et al, 2022; Husted Nielsen I, et al, 2022.

Parkinson's Caregiver peer mentoring: Feasible, high satisfaction



- 34 former or active experienced caregivers completed training
- 51 of 61 eligible caregivers of homebound Parkinson's participants enrolled, 3 withdrew
- Median of 11 calls in 16 weeks, 30 minutes' duration (IQR 20-45)
- Mean satisfaction 91/100
- Over one year of home visits + peer mentoring: Greater baseline strain than non-equivalent controls, stable over one year while control caregivers worsened

J.E. Fleisher et al.

Parkinsonism and Related Disorders 106 (2023) 105222

Table 3

Comparison of overall and dimension-specific caregiver strain between IN-HOME PD and POP caregivers.

	IN-HOME-PD Caregivers				POP Caregivers				
	N	Baseline	1 year	p [1]	N	Baseline	1 year	p [1]	p ²
Multidimensional Caregiver Strain Index, mean (SD)									
Total caregiver strain	47	23.34 (9.43)	24.32 (9.72)	0.51	154	16.45 (10.33)	17.97 (10.88)	0.01*	0.73
Physical strain	49	4.27 (3.09)	4.69 (2.75)	0.33	156	2.76 (2.54)	3.13 (2.96)	0.03*	0.90
Social constraints	48	7.83 (3.41)	8.13 (3.69)	0.60	156	5.93 (3.86)	6.23 (3.86)	0.16	0.99
Financial strain	49	1.41 (1.64)	1.51 (1.84)	0.68	154	0.62 (1.07)	0.71 (1.08)	0.28	0.97
Time constraints	49	4.61 (1.82)	4.55 (2.01)	0.86	156	3.24 (2.33)	3.59 (2.15)	0.02*	0.27
Interpersonal strain	49	4.04 (3.45)	4.02 (3.28)	0.96	156	2.73 (2.52)	3.07 (2.94)	0.08	0.38
Demanding/manipulative	48	1.06 (1.39)	1.15 (1.52)	0.72	155	1.19 (1.61)	1.25 (1.51)	0.64	0.89

Learning to PERSEVERE



Peer Mentor Support and Caregiver Education in Lewy Body Dementia

- Focus groups of former mentors, former mentees, and *de novo* Parkinson's & LBD family caregivers to review & revise curriculum
- ENTIRELY virtual; opened recruitment nationally in partnership with LBDA & PF email lists & Facebook groups
- Trained 36 new mentors virtually from across the US



NIA



What information do caregivers want?



Weeks	Social Support Topics	LBD Mastery Topics
1-2	Introductions, expectations, goal setting	Top concerns of mentee/goals for mastery
3	Relationship building, top concerns	Falls, fall prevention
4-5	Caregiver strain and related outcomes	Home safety and resources for aging-in-place
6-7	Support system, isolation, loneliness	Depression, anxiety, apathy
8-9	Self-care for caregiver	Hallucinations & delusions
10-11	Guilt and anger, changing roles	Constipation & orthostatic hypotension
12-13	LBD unpredictability	Sudden changes/infections – detection, management; advocating in the ER/hospital
14-15	Anticipatory grief , remaining needs, goal-setting for future	Advance directives – planning & starting the conversation
16	Reflecting on PERSEVERE, concluding mentor relationship	Review sudden changes, fall prevention & home safety, non-motor symptoms, presence of advance directives

Despite active caregiving demands or bereavement, caregivers prioritized Learning to PERSEVERE

- 30 mentor-mentee pairs completed 424 calls (15 calls/dyad, median 45 min)
- 100% found calls useful; 100% would recommend to other caregivers
- 90% of mentors would serve as mentors in future
- **50% of mentees would serve as mentors in future**

Results of Stage Ib: Learning to PERSEVERE (2020-2021)			
Assessment	Baseline mean (SD)	Post-mentoring mean (SD)	p-value
Mentor Outcomes : n = 30			
LBD Knowledge Test	55.83 (13.34)	64.72 (12.70)	0.01
Dementia Attitudes Scale	120.97 (11.76)	121.60 (11.81)	0.66
Mentee Outcomes : n = 28			
LBD Knowledge Test	50 (10.14)	56.85 (14.88)	0.02
Pearlin Mastery scale	32.46 (7.57)	33.04 (6.82)	0.58
Dementia Attitudes Scale	104.25 (13.58)	111.57 (9.38)	0.001
Geriatric Depression Scale	5.0 (3.76)	4.22 (3.19)	0.04
Zarit Burden Interview – Short form	23.18 (8.25)	22.18 (8.52)	0.30

National, randomized controlled trial of peer mentor support and caregiver education in LBD and Parkinson's Dementia



Can an LBD-specific, caregiver-centered educational intervention improve caregiver knowledge, confidence, strain, and health outcomes – and PLBD outcomes, too?



Study Overview

- Virtual format, open to both current & past LBD family caregivers in US and US territories
- Experienced (3 or more years) or former caregivers → **Peer mentors**
 - Will be trained virtually by study team and paired with a caregiver mentee for 12 weeks of weekly mentor check-ins
 - Up to three sequential mentees over 2-3 years
 - Monthly videoconference support meetings while actively mentoring
- Caregivers with community-dwelling loved ones with LBD for <2-3 years, randomized 1:1 to 12-week intervention + 6 months' follow-up:
 - **Mentees:** PERSEVERE curriculum + weekly mentoring calls
 - **Attention control:** Lighter intervention, one-hour LBD webinar, weekly email with links to pre-existing content (~30-45 minutes/week)

Participant criteria - Caregiver

- Must be a family caregiver of a loved one with Parkinson's Dementia, Parkinson's with visual hallucinations or Dementia with Lewy Bodies
- Loved one must have cognitive symptoms for less than three years
- Must live with or spend at least 10 hours/week caregiving currently
- Must live in the US, have a phone and internet, and be comfortable speaking and reading English

Participant criteria – Mentor

- Must be a family caregiver of a loved one with Parkinson's Dementia, Parkinson's with visual hallucinations or Dementia with Lewy Bodies
- More than 2 years' experience as a caregiver since onset of cognitive symptoms OR loved one deceased
- IF loved one is alive: Must live with or spend at least 10 hours/week caregiving currently; if loved one is deceased, must have met those criteria while alive
- Must live in the US, have a phone and internet, and be comfortable speaking and reading English

**Underrepresented caregivers of particular interest:
Black, Latinx/Hispanic, Male, Rural-Dwelling**



Interested in learning more or participating?

- Scan the QR code to the left!
- Visit <https://redcap.link/PERSEVERE1> to watch a video with more information about the study
- Listed on clinicaltrials.gov, [Fox Trial Finder](https://www.fox.com), [alzheimers.gov](https://www.alzheimers.gov), [LBDA.org](https://www.lbda.org), [The New Normal](https://www.thenewnormal.org)
- **Email us directly at** persevere@rush.edu



Conclusions

- Parkinson's family caregivers have higher strain & burden than caregivers for individuals with Alzheimer's Disease
- Risk factor on its own for loved one's hospitalization and institutionalization
- Potentially modifiable with peer mentor-led educational intervention
- *Despite high strain and burden, caregivers can share invaluable lived experience + train as mentors to newer caregivers...*
 - *Who improve their own knowledge and attitudes...*
 - *And want to serve as future caregiver peer mentors, **creating a pipeline!***

Acknowledgments

NYU Home Visit Program & Rush IN-HOME-PD Patients, Families, and Peer Mentors

Rush Home Visit & PERSEVERE Team:

- Serena Hess, MA MSN, Jeanette Lee, LCSW, Daniela Mitchem LSW, Ellen Klostermann Wallace, PhD, Faizan Akram, Erica Myrick, Melissa Levin, Kat Woo; Wdasie Ayele, Jess Hemm, Sarah Mitchell Chen LCSW APHSW-C, LBD Caregiver Advisory Panel

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- Neha Kramer MD, Sarah Mitchell Chen, LCSW, Kristin Gustashaw RD, Grace Hong RN, Dirk Labuschagne MDiv MPH

Mentors and Advisors:

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Rush University Medical Center

Pearls to Take Home: Practical Strategies for Improving Daily Living in Parkinson's

Davis Phinney Foundation
Victory Summit
Green Bay, WI
October 11, 2024

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OVERVIEW

- Handwriting
- Food preparation
- Eating & hydrating
- Dressing & footwear
- Transfers, mobility, and getting out & about
- Hygiene
- Toileting
- Communication
- Orthostatic hypotension
- Hospital beds
- Medication adherence

Disclosure

We have never received any financial benefits for ANY of the products listed. Please do not take any of these tips as paid endorsements.

MANY of the products and life hacks have been suggested by patients and care partners – so THANK YOU & keep the ideas coming



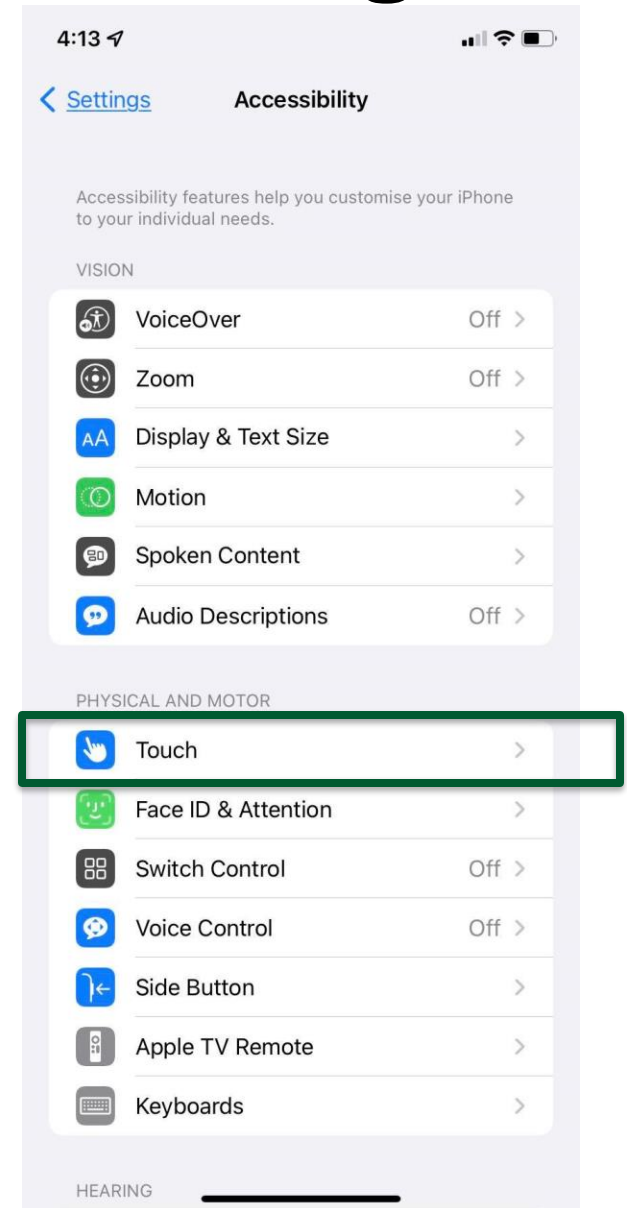
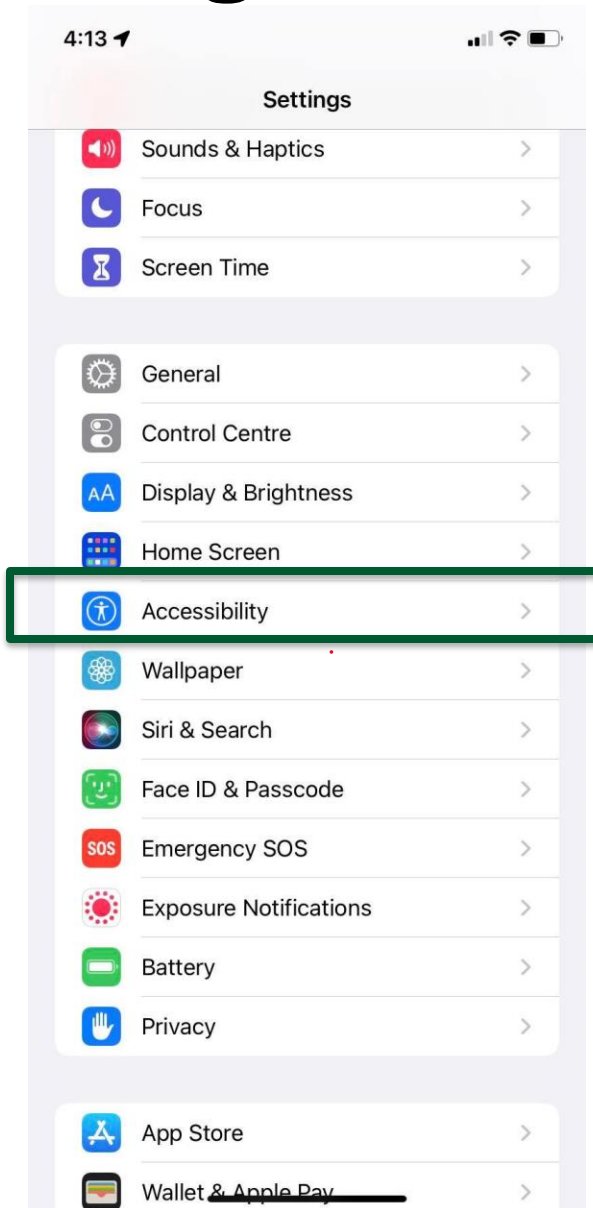
HANDWRITING



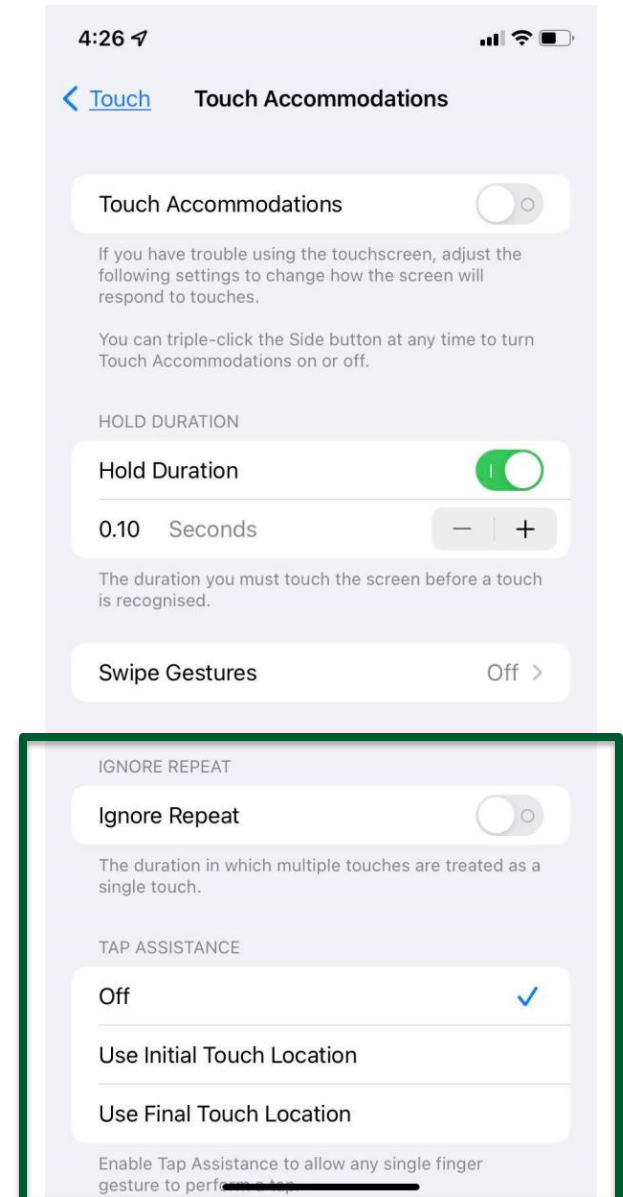
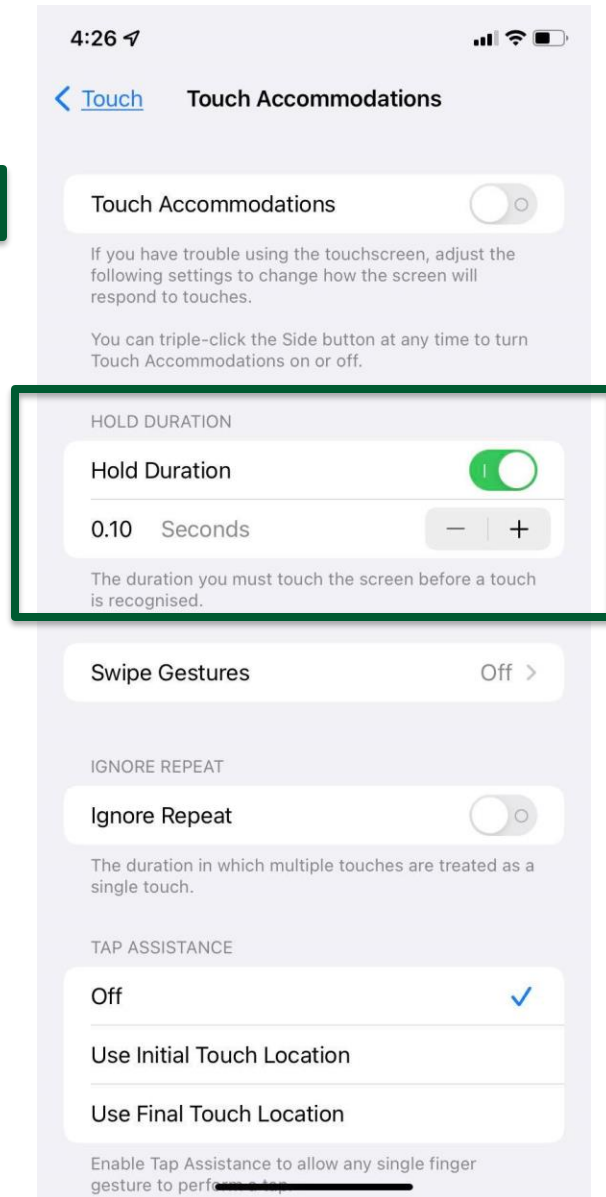
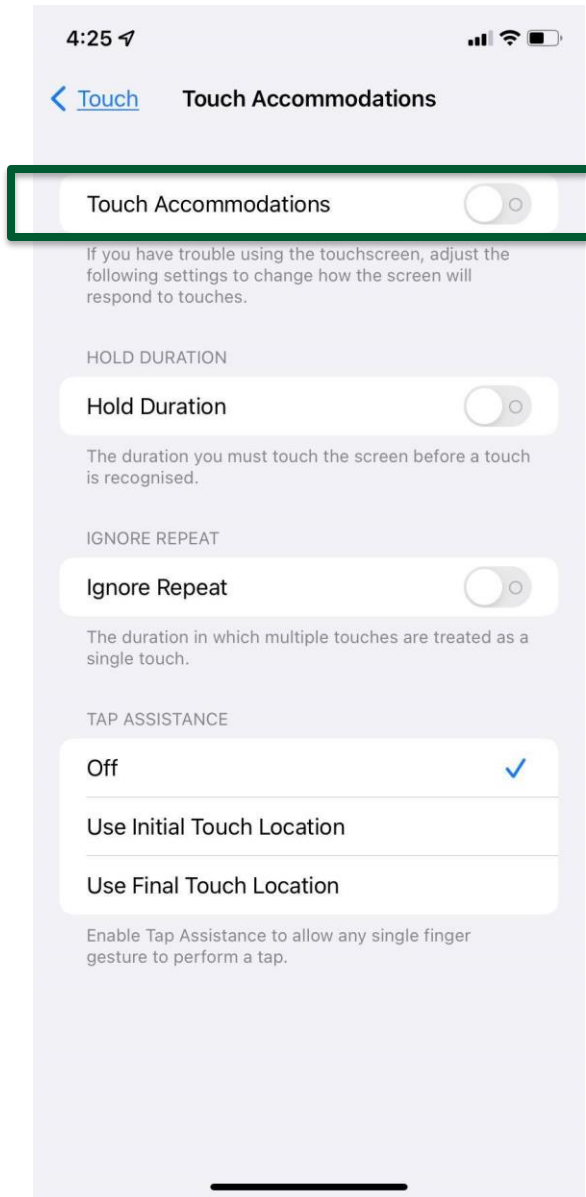
Adjusting iPhone Settings



Settings



Adjusting iPhone Settings



FOOD PREPARATION



ACTIVITIES OF DAILY LIVING



EATING



Plates with rims



Silicone placemat



Nosey cups



Pizza cutter or
mezzaluna/rocking
knife instead of
regular knife



EATING



Weighted
utensils



Easy grip jar
opener



One-touch can
openers
("Kitchen Mama")

STAY HYDRATED!



WHY?

- People with PD are at higher risk of dehydration
- Dehydration → Confusion, urinary tract infection, fatigue, lightheadedness, dizziness, falls, and constipation

HOW:

- Hot or iced tea, decaf coffee
- “Spa water” with fruit slices or herbs
- Crystal Light, Mio, Dasani, Kool Aid
- ALL THE FRUIT! (well, except bananas)
- Water bottle you like: size, shape, grip-, gulp-, cleanabilities



DRESSING

Amazon Best Sellers

Our most popular products based on sales. Updated hourly.

Best Sellers in Daily Living Sock & Stocking Aids

#1



RMS Deluxe Sock Aid - Socks Helper with Foam Handles
★★★★☆ 9,147
\$9.95 ✓prime

#2



Vive Sock Aid - Easy On and Off Stocking Slider - Donner Pulling Assist Device - Sock Helper Aide...
★★★★☆ 4,981
\$9.99 ✓prime

#3



Carex Sock Aid Easy On Easy Off, Sock Slider and Sock Assistance Device, for Those with Limited...
★★★★☆ 964
\$8.49 ✓prime

#4

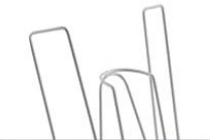


Allstar Innovations - Sock Slider - The Easy on, Easy off Sock Aid Kit & Shoe Horn | Pain Free No...
★★★★☆ 3,033
\$19.91 ✓prime

#5



#6



#7



#8



Lands' End School Uniform
Men's A... Interlock Polo Shirt

Lands' End

★★★★☆ 1



MagnaReady.com
Silverts.com

Target or Amazon: search "adaptive clothing"



Adaptive Clothing for Women



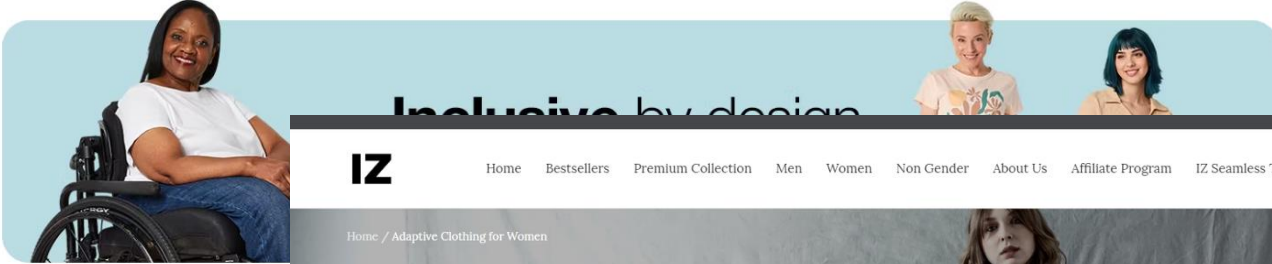
What can we help you find? [Search]

North Riverside... My Account Sign In [Cart]

- Back To School Trending Now Home & Lifestyle Women Men Young Adult Baby & Kids Shoes & Accessories Jewelry Beauty & Salon Inspiration Sale

women > Women's Adaptive Clothing & Accessories

Women's Adaptive Clothing & Accessories



- Home Bestsellers Premium Collection Men Women Non Gender About Us Affiliate Program IZ Seamless Technology™



Home / Adaptive Clothing for Women

Adaptive Clothing for Women

Women's fashion has always been a way to showcase individuality and unique style. From runways to city streets, clothing is used to make a statement. Our adaptive clothing creates fashionable and functional clothing for wheelchair users and people living with limited mobility. These modern timeless classic pieces are designed with the needs of our customers in mind.

Show filters 55 products

Sort by Date, new to old



Joeandbella.com

Izadaptive.com




Ovidis.com

JCPenney.com & search "adaptive clothing"

FOOTWEAR



Accessories **kizik** Learn Rewards Exchanges & Returns

Black (Black Outsole) Men's Roamer \$149	Graphite Men's Madrid Eco-Knit \$99	Cinder Brown Men's Lima \$1
Men's 	Men's 	Men's 
Deep Sea Men's Athens \$129	Cognac Men's Vegas \$129	Dusk Blue Men's Prague \$1

Zeba.com

Kizik.com

Nike.com: Nike Go FlyEase

BOTH have men's and women's shoes; sneakers & less casual



Foot cramps



YogaToes



1. Buy can of frozen juice concentrate
2. Make juice (or defrost & use for smoothie)
3. Refill can with water and freeze **upright**
4. **When soles of feet are cramping, press and roll sole of foot over frozen can**
5. Refreeze & repeat

Tennis ball is similar, just missing cold benefit

TRANSFERS

(The Plastic Bag Trick)



TRANSFERS

\$\$ version of the Plastic Bag Trick: Lazy Susan/Steven



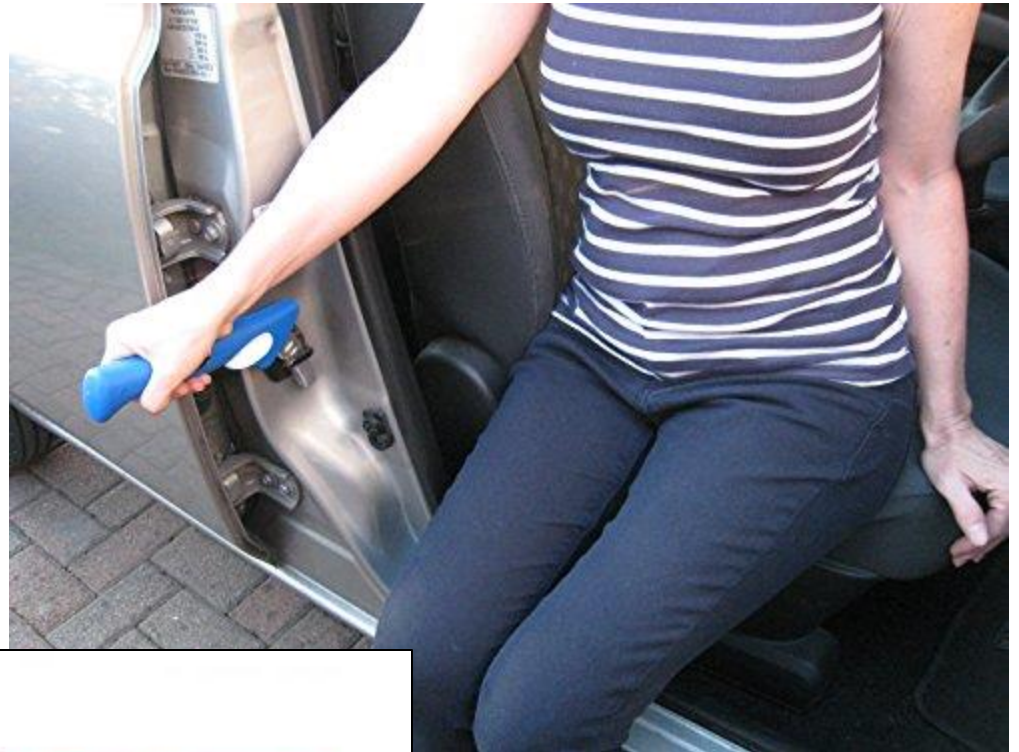
Amazon: “Swivel Seat Cushion”

Bonus – you can use on other non-swiveling chairs at home!

TRANSFERS



Seat belt extender
(hard plastic kind)



“Car assist handle”
(literally 100s on
Amazon; they all work
the same way)

TRANSFERS AND BED MOBILITY



Search Amazon or Google for “bed cane”

Silky or satiny pajamas
OR silky or satiny sheets
(NOT. BOTH.)



TRANSFERS AND BED MOBILITY



**GREATER
STABILITY
MINIMIZES
INJURY RISK**

Search Amazon or Google for
“sit to stand device”

**Insurance does not cover these.
Check your local lending
closet!**

TRANSFERS AND BED MOBILITY



Search Amazon or Google for
“Hoyer lift”

Insurance may cover these with appropriate documentation from physician and a recent face-to-face visit.

Also: Check your local lending closet!

GAIT BELTS



Search Amazon or Google for “Cow&Cow gait belt” – check sizing guide

Can be used in shower!



SEATING

Search Amazon
or Google for
“sacral gel pillow”



OUT & ABOUT

- Transport wheelchair
 - Easy to put in & out of vehicle and for short distances/trips
 - NOT meant to be a daily use/all-day wheelchair
 - **Dumb Medicare Rule #1:** Medicare covers only ONE wheelchair every five years (similarly, only ONE walker every five years)
 - SO... buy a transport chair out of pocket, borrow one, or contact a lending closet
 - DON'T spend Medicare \$\$ on this; save that for a better chair in case you need it!



OUT & ABOUT

- Trick out your chair handles to make caregiver's hands & back happier!
 - Hard plastic grips that come standard → calluses & discomfort
 - Brilliant life hack:
 - Take your transport (or daily) wheelchair to a BIKE SHOP
 - Ask the owner/staff to remove the hand plastic grips and replace them with ergonomic, comfy bike handlebar grips
 - They may need to use a box cutter to remove the old ones, and hair spray on inside of new grips to slide over metal bar



HYGIENE



← Gillette Treo

Guide Beauty →



Guide Eyeliner Duo |
Applicator & Long-...

\$50.00
Guide Beauty
Free shipping

Easy On The Eyes
Brush Collection

\$50.00
Guide Beauty
Free shipping

ORAL HYGIENE



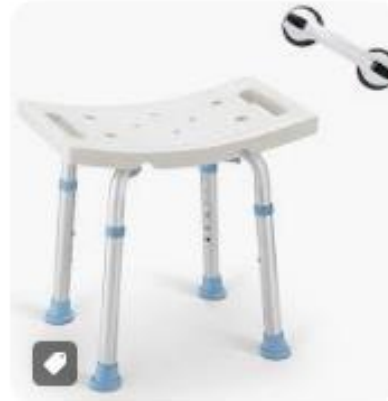
BATHING



[Amazon.com](#) · In stock
Medline Shower Chair Ba...



[Walmart.com](#) · In stock
Drive Medical Bathroom S...



[Amazon.com](#) · In stock
Amazon.com: OasisSpace S...

← “Shower chair”

“Shower transfer bench” or
“tub transfer bench” →



[Amazon.com](#) · In stock
Tub Transfer Bench For Bathtub ...



[Amazon.com](#) · In stock
DMI Heavy-Duty Sliding Trans...

BATHING



“Handheld shower head” to use while seated on shower chair



“Long-handled bath sponge”

BATHING

“Non-skid bath stickers” or
“non-skid bath tape” →

PRO-TIP: Not just for the shower or bath! Use this or **brightly colored duct or painter’s tape** at doorways or flooring changes that lead to freezing of gait



TOILETING



TOILETING



Search Amazon or Google for:
“bedside commode”
“raised toilet seat” (check to see if your toilet has a round or oval shaped bowl!)
“Tushy” bidet (adds to existing toilet)

TOILETING – Men’s Edition



Search Amazon or Google for:
“bedside urinal” or “portable urinal”



Search Amazon or Google for:
“Quickchange.com”

TOILETING – Women’s Edition



Search Amazon or Google for:
“Loona: personal portable urinal”



Search Amazon or Google for:
“Shewee”

COMMUNICATION



COMMUNICATION

Google “communication board” for a host of different versions to print, copy, & laminate



COMMUNICATION

Search the App Store or wherever you download applications for “SmallTalkConversationalPhrases”



SmallTalkConversationalPhrases 4+

Aphasia Communication App

[Lingraphica, Inc.](#)

★★★★★ 4.3 • 6 Ratings

Free

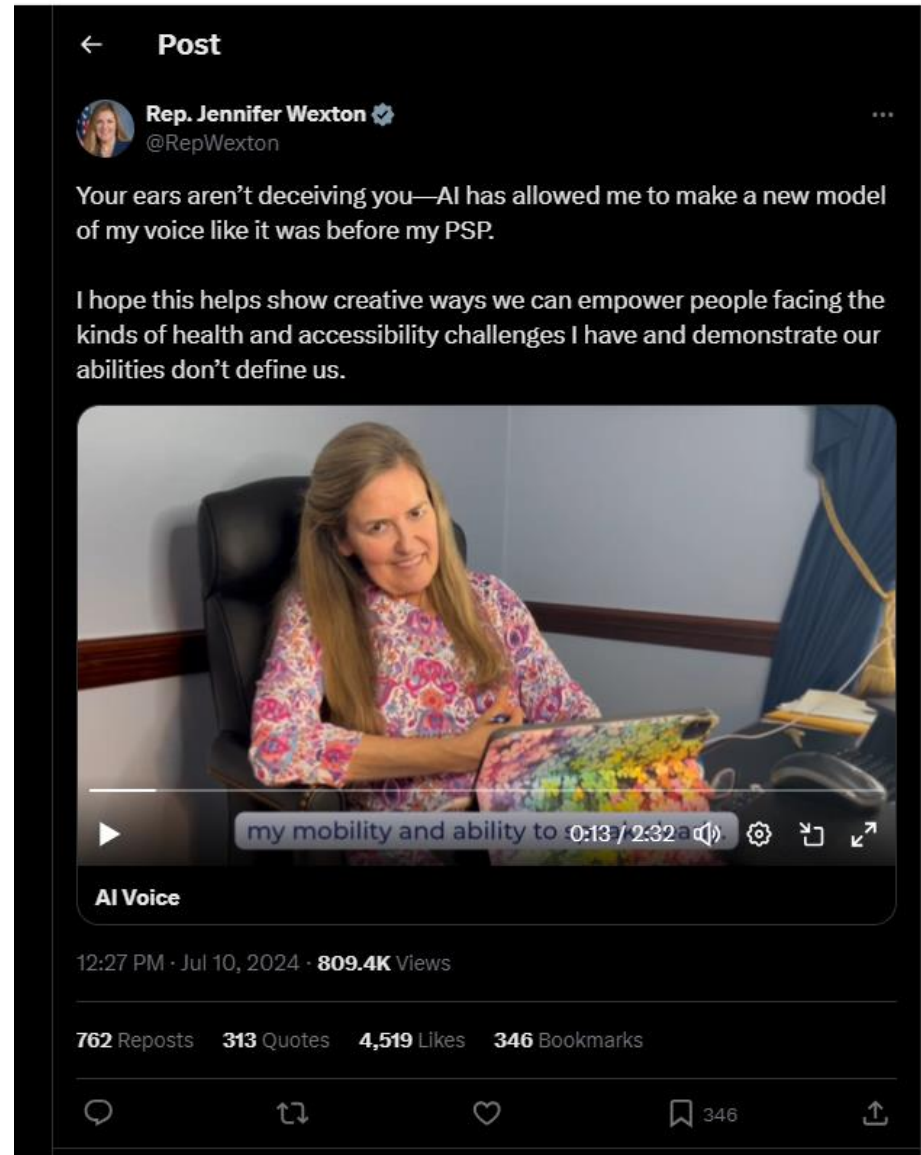
Screenshots [iPhone](#) [iPad](#)





COMMUNICATION

Coming soon...

[Representative Wexton speaking with AI voice model](#)








← Post

 **Rep. Jennifer Wexton** 
@RepWexton

Your ears aren't deceiving you—AI has allowed me to make a new model of my voice like it was before my PSP.





I hope this helps show creative ways we can empower people facing the kinds of health and accessibility challenges I have and demonstrate our abilities don't define us.


my mobility and ability to 0:13 / 2:32    

AI Voice

12:27 PM · Jul 10, 2024 · **809.4K** Views

762 Reposts **313** Quotes **4,519** Likes **346** Bookmarks

    346 

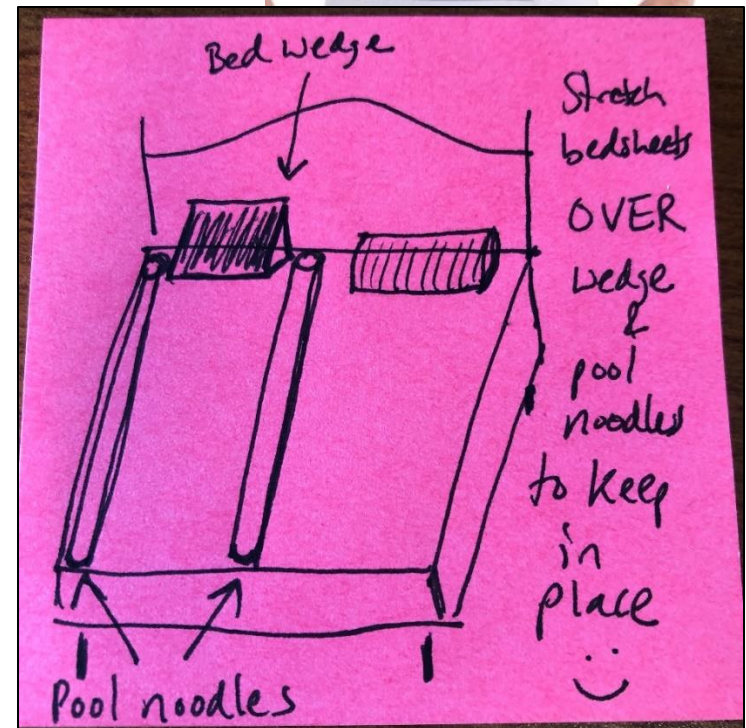
ORTHOSTATIC HYPOTENSION



Search Amazon or Google for:
“bed wedge”
“abdominal binder”



Target or Dollar Store
for pool noodles



Hospital Beds

Medicare Part B (Medical Insurance) covers hospital beds as durable medical equipment (DME) that your doctor prescribes for use in your home.

Your costs in Original Medicare

After you meet the Part B Deductible, you pay 20% of the Medicare-Approved Amount (if your supplier accepts assignment). Medicare pays for different kinds of DME in different ways. Depending on the type of equipment:

- You may need to rent the equipment.
- You may need to buy the equipment.
- You may be able to choose whether to rent or buy the equipment.

Medicare will only cover your DME if your doctors and DME suppliers are enrolled in Medicare. Doctors and suppliers have to meet strict standards to enroll and stay enrolled in Medicare. If your doctors or suppliers aren't enrolled, Medicare won't pay the claims they submit.

Make sure your doctors and DME suppliers are enrolled in Medicare. It's also important to ask a supplier if they participate in Medicare before you get DME. If suppliers are participating in Medicare, they must accept assignment (which means, they can charge you only the coinsurance and Part B deductible for the Medicare-approved amount). If suppliers aren't participating and don't accept assignment, there's no limit on the amount they can charge you.

Hospital Beds – Part 2

- **Dumb Medicare Rule #2:** “Hospital bed” that is covered by Medicare is “adjustable” not fully electric
- HOSPICE agencies can provide a hospital bed that they pay for and rent to you (for free) that is often better than what Medicare would cover

Hospital Beds – Part 3

- **Low-pressure mattresses (pressure wounds):**
 - **Dumb Medicare Rule #3:** ONLY covered if MULTIPLE pressure wounds of advanced stages are present and documented in the medical record
 - They CAN cover a gel overlay pad if it's included in the hospital bed order from a physician
 - Alternative (out of pocket):
 - Purap mattress pad (~\$400)
 - Search Amazon or Google “gel overlay for hospital bed”



Lending Closets

- Many towns/villages/municipalities have lending closets. People can donate equipment to them and rent equipment from them, usually at low or no cost.
 - Calling the local Area Agency on Aging or Village/Town Hall can get people routed to the appropriate local lending closet.
 - This link includes many areas in and around Chicago:
<https://www.elderwerks.org/fg/content/articles-and-guides/medical-lending-closet-lists-of-providers-022caa4e-ff57-4797-9a85-846750490cb7-1.aspx>
- Or check out: devices4thedisabled.org They accept donations of wheelchairs, beds, walkers (including UStep walkers), and other equipment and then redistribute them for free.
- **NO, unfortunately, Rush will NOT accept used equipment to pass along to other families for legal reasons ☹️**

MEDICATION ADHERENCE

- Link each dose with a regular activity, keep pills in those locations:
 - brushing teeth
 - making coffee
 - reading the paper



MEDICATION ADHERENCE

- Set reminders
 - Sticky note reminders in specific locations
 - Pillboxes with built-in alarms
 - Google or Amazon:
 - e-pill 4 Alarm Pill Box Organizer with Vibration Reminder
 - Med-E-Lert Pill Box Dispenser



MEDICATION ADHERENCE

- Set phone alarms:
 - Most cellphones (including flip phones) can handle at least 3 alarms daily
 - Multiple alarms, can each be set & labeled for different medications
 - Can use different ringtones for different medications



MEDICATION ADHERENCE

- Set reminders: High-tech:
 - Use your smartphone-- there's an app for that!
 - Many pharmacies have apps of their own
 - Many other FREE pill reminder apps, different bells & whistles, can connect to your pharmacy, track symptoms, find coupons
 - MedHelper
 - MedSimple
 - MedCoach
 - MediSafe
 - Pill Reminder

MEDICATION ADHERENCE

- Keep an emergency supply in your purse or wallet, glove compartment, **carry-on bags**
- Bring medications with you to the hospital
- Ask an occupational therapist for other ideas tailored to your life



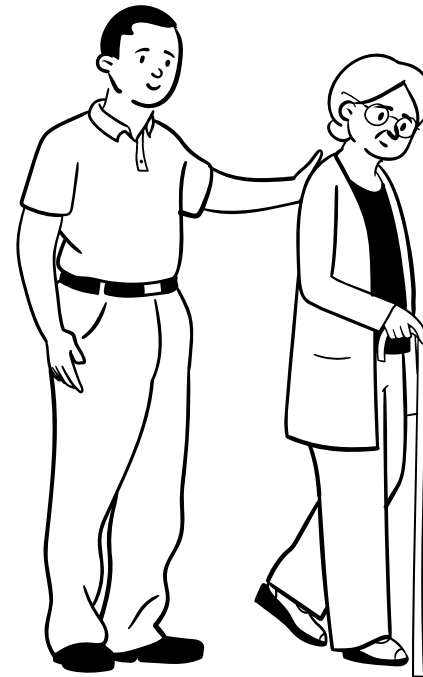


**A National Study for Lewy Body Dementia
Family Caregivers**

Jori Fleisher, MD MSCE
Principal Investigator



Can a Lewy Body-Dementia-specific, caregiver-centered educational intervention improve caregiver knowledge, confidence, strain, and health outcomes
– and can it help people with LBD, too?



Why?

- No current effective PD or DLB specific caregiver interventions
- Current effective interventions for dementia (usually Alzheimer's) are costly
- Paid caregivers – not covered by insurance, expensive, hard to find, high turnover rate, and minimal training in dementia, PD, DLB, and end-of-life care

Study Goals

- Reduce caregiver strain
- Promote caregiver knowledge, mastery, and attitudes
- Show that providing a mentor to caregivers of people living with Lewy Body Dementia (PLBD) is beneficial

Prior work

JMIR RESEARCH PROTOCOLS

Fleisher et al

Protocol

Peer Mentoring Program for Informal Caregivers of Homebound Individuals With Advanced Parkinson Disease (Share the Care): Protocol for a Single-Center, Crossover Pilot Study

Jori E Fleisher¹, MD, MSCE; Faizan Akram¹, BSc; Jeanette Lee¹, LCSW; Ellen C Klostermann¹, PhD; Serena P Hess¹, RN, MSN, MA; Erica Myrick^{1,2}, MS; Melissa Levin^{1,3}, BA; Bichun Ouyang¹, PhD; Jayne Wilkinson^{1,4}, MD, MSCE; Deborah A Hall¹, MD, PhD; Joshua Chodosh^{5,6}, MD, MSHS

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Contents lists available at ScienceDirect



ELSEVIER

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkrelidis



IN-HOME-PD Caregivers: The effects of a combined home visit and peer mentoring intervention for caregivers of homebound individuals with advanced Parkinson's disease

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ORIGINAL ARTICLE

Family Caregiver Comorbidities in Lewy Body Dementia Versus Alzheimer Disease and Associated Disorders

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Faizan Akram, BS,* Serena P. Hess MA, MSN, RN,*
Madhuvanathi Suresh PhD,* Cintra D. Bentley,§ Thomas Manak, MA,§
Maraline Mattke, LCSW,§ Allegra Miller,§ Claire E. PennsyL,§
Carmen M. Pierce,§ Margaret Voss § Angela Taylor,||
Karlin Schroeder, MA,¶ and Joshua Chodosh, MD, MSHS#**

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Learning to PERSEVERE: A pilot study of peer mentor support and caregiver education in Lewy body dementia

Jori E. Fleisher^{a,*}, Madhuvanathi Suresh^a, Melissa E. Levin^{a,b}, Serena P. Hess^a, Faizan Akram^a, Danielle Dodson^c, Michelle Tosin^a, Glenn T. Stebbins^a, Katheryn Woo^a, Bichun Ouyang^a, Joshua Chodosh^{d,e}

Study Overview

- Virtual format
- 9 months of bi-weekly surveys
- Experienced (3 or more years) or former caregivers → Peer mentors
 - Will be trained virtually by study team and paired with a caregiver mentee for 12 weeks of weekly mentor check-ins
- Caregivers with loved ones with LBD for <2 years:
Randomized 1:1 to two different intervention groups:
 - Half will be assigned to the active intervention group
 - Half will be assigned to the lighter intervention group
 - Participate in a one-hour webinar on LBD
 - Emailed links to caregiver resources weekly

Resources include:

- Links to accredited resources
- LBD specific content explaining symptoms and prognosis
- Caregiver needs and coping
- Mentor check-ins
- Virtual reality vignettes

Who are the mentors?

- People with at least 2 and often 3 or more years of caregiving experience
- Some have been mentees or mentors in previous studies looking to pay it forward; total of 120 mentors needed
- Attend live talks on LBD symptoms, mentoring, study expectations, review of the PERSEVERE handbook, its use in weekly mentoring calls, and safety protocols
- Meet monthly with the study social worker for additional support

Why mentor?

“There’s so many things I wish I knew when I was doing it. And I’ve learned so much and I want to impart the intellectual knowledge. But I also want to provide the empathy and the support to somebody who’s been in my shoes, who I’ve been in their shoes, and just be able to tell that person I do understand. I have been there and provide them with whatever support I can.”

—LBD caregiver and mentor

What topics will be covered in all groups?

Weekly PERSEVERE topics		
Week	Social Support Topics	LBD Knowledge Topics
1	Introductions, expectations, finding joy & patience	Top mentee concerns
2	Relationship building, goal setting	Falls & fall prevention
3	LBD caregiver strain, comorbidities, & outcomes	Depression, apathy, and anxiety
4	Isolation, loneliness, and support	Cognition, fluctuations, visuospatial changes, & sleep disorders; understanding palliative care
5	Changing roles, managing guilt & anger	Hallucinations & delusions
6	Self-care caregivers: what, why, and how	Watch virtual reality (VR) LBD modules
7	LBD unpredictability, advance directives, serious conversations	Constipation, blood pressure, and other symptoms of dysautonomia
8	Advocating for care (ER, hospital, institutions)	Sudden changes: detection, management
9	Understanding health coverage & housing for LBD (Medicare, Medicaid, in-home & institutional care)	LBD medications & medication management; VR caregiver burnout & med safety modules
10	Anticipatory grief, ambiguous loss, future planning	Weight loss; review sudden changes, safety, falls
11	Grief and life beyond caregiving	Understanding hospice: what, when, & why
12	Reflection & mentoring relationship conclusion	Review symptoms, advance directives, self-care

Participant criteria - Mentee

- Must be a family caregiver of a loved one with PD Dementia, PD with visual hallucinations or Lewy Body Dementia
- Your loved one must have cognitive symptoms for less than three years
- Must live with or spend at least 10 hours/week caregiving currently
- Must live in the US, have a phone and internet, and be comfortable speaking and reading English

Participant criteria – Mentor

- Must be a family caregiver of a loved one with PD Dementia, PD with visual hallucinations or Lewy Body Dementia
- More than 2 years experience as a caregiver OR your loved one had deceased
- Must live with or spend at least 10 hours/week caregiving currently
- Must live in the US, have a phone and internet, and be comfortable speaking and reading English



What past participants are saying

“You needed not only that knowledge, but you needed someone to just understand what you were going through, because these these diseases are very different than what other people go through. And then it's such a different journey for everybody. So to even be able to share just a little bit of insight into what to anticipate, and what to look for is so helpful”

—LBD caregiver and mentor

“I wish I had been given [the handbook] the moment my mother was diagnosed. It would have saved a lot of worry, tears, and frustration.”

—LBD Caregiver

“It was a good guidance tool and has wonderful references for helping with getting information into the hands of the mentees.”

—LBD Caregiver

“What I guess I learned through all of it is that we do get through it. And I think the other thing I learned is that I can help others to get through it. I would not have thought that about myself, and yet I have two sisters who are going through similar situations now, and they call me regularly for help. And my mentee—we've become very close, and we see each other at least once a month. We meet and we talk. That was a wonderful experience for me...strengthening experience...and I truly feel that I can help others”

—LBD caregiver



Interested?

- Email us at persevere@rush.edu

To see if you are eligible, scan the QR code to fill out our screening survey OR visit

<https://redcap.link/PERSEVERE1>



SHOW & TELL: What are YOUR tricks & hacks?



PROGRAMS / PARKINSON'S CARE PARTNER TRAINING



Visit dpf.org/im-a-care-partner to access additional resources including our Care Partner Training, a 10-session, self-paced training lead by the team behind today's workshop.