

ILLINOIS CHAPTER

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Up to 80% of people with Parkinson's disease experience sleep difficulties.

BETTER SLEEP BRIGHTER DAYS

Sleep: A Core Part of Parkinson's Care

Up to 80% of people with Parkinson's disease (PD) experience sleep difficulties. These issues can appear early and often change over time. While common, sleep problems are treatable—and improving sleep can boost mood, thinking, mobility, and overall quality of life.

Common Sleep Difficulties in PD

Sleep challenges in PD can include:

- Insomnia – Trouble falling or staying asleep
- Excessive daytime sleepiness – Overwhelming tiredness or sudden “sleep attacks”
- Restless legs syndrome (RLS) – Urge to move the legs at night
- REM sleep behavior disorder (RBD) – Acting out dreams during sleep
- Obstructive sleep apnea (OSA) – Snoring, breathing pauses, frequent awakenings
- Circadian rhythm changes – Shifts in the body's internal clock

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NOTE FROM EXECUTIVE DIRECTOR

As we welcome spring, a season of renewal, we're reminded that hope springs eternal. And as the days grow longer and bring more light, many of us feel that quiet lift: a fresh start, a little more energy, and a reason to look ahead with optimism.

This spring, we're especially grateful for the "new beginnings" happening across our APDA community. We're blessed to welcome many individuals and families who are new to Parkinson's and new to APDA—people reaching out for trusted information, practical tools, and a place to feel understood. What inspires us most is how quickly connection happens here. You support one another with encouragement, shared resources, and the kind of understanding that only comes from walking a similar path. You remind us that no one has to face Parkinson's alone.

At the same time, we're encouraged by the continued progress

in Parkinson's research. Momentum is building, discoveries are advancing, and each step forward moves us closer to better treatments, and ultimately a cure.

I hope this newsletter provides you with knowledge and resources as we plan for a very hope-filled spring full of connections and friendships, learning and growth.

I look forward to seeing you at an upcoming APDA event soon. Be sure to bring a friend, or plan on making a new one.

Yours In Service,
Melanie Adams
Executive Director
APDA Illinois Chapter



PD CLINICAL TRIALS

Clinical trials play a vital role in advancing Parkinson's research and developing new treatments—and ultimately, a cure.

APDA provides access to information on ongoing clinical trials across the country, all reviewed and approved by Institutional Review Boards.

Scan the QR code to learn more about current studies and how research is moving Parkinson's care forward.



OR VISIT:
<https://www.apdaparkinson.org/research/clinical-trials/>

BETTER SLEEP, BRIGHTER DAYS: A Mental Health Guide to Rest and Renewal



Kathleen Matthews PhD
Geropsychologist & Founder
Perennial Pathways

These issues often stem from a mix of brain changes, medications, nighttime motor symptoms, mental health conditions, and age-related sleep changes.

Why Sleep Matters

Sleep affects how we feel, think, and move:

- **Mood:** Anxiety or depression disrupt sleep; poor sleep worsens emotional resilience.
- **Thinking:** Fatigue affects attention, memory, and judgement.
- **Movement:** Exhaustion worsens motor symptoms and increases fall risk.
- **Relationships:** Sleep loss can strain families and intimacy.

Improving sleep means clearer thinking, steadier movement, and improved quality of life.

What We Know About Medications

Medication options for sleep in PD are limited. Melatonin, dopamine therapies, or wake-promoting agents may help some, but research is mixed. Sleeping pills can offer short-term relief but raise risks of confusion, falls, and next-day grogginess. Non-drug strategies are the safest starting point.

Your Sleep Toolkit

1. **Keep a Consistent Routine**
 - Go to bed and wake up at the same time daily.
 - Get morning light within 1 hour of waking.
2. **Use Light Wisely**
 - Morning: 20–30 minutes outdoors before 10 a.m.
 - If indoors: Use a 10,000 lux light box for 20–30 minutes.
 - Evening: Dim lights 1–2 hours before bed.
3. **Move Your Body**
 - Aim for 150 minutes of moderate activity weekly—adapt to your abilities.
 - Avoid vigorous exercise within 2 hours of bedtime.
4. **Wind Down Mindfully**
 - Spend 30–60 minutes on calming activities—reading, gentle music, stretching, or breathing exercises.
5. **Nap Smartly**
 - Limit naps to 10–30 minutes; avoid late afternoon naps.
6. **Create a Sleep Friendly Environment**
 - Keep the bedroom cool (60–67°F), dark, and quiet.
 - Use the bed only for sleep and sex.
 - Add nightlights for safety; remove sharp edges if at risk for falls or RBD.
7. **Address Nighttime Symptoms**
 - Avoid caffeine after 2 p.m.
 - Limit fluids 2–3 hours before bed.
 - Avoid screens 30–60 minutes before bed.
 - Talk with your provider about pain, stiffness, or medication timing.
8. **Calm Your Mind, Reset Your Focus**
 - Notice and name thoughts—label them (“planning,” “worrying”) without judgment and let them pass.



- Focus on sensations—breath, sheets, sounds.
- Remind yourself: “It’s okay to rest without sleeping.”

9. Support Mental Health

- For chronic insomnia, evidence-based therapies delivered by qualified mental health professionals—such as Cognitive Behavioral Therapy (CBT) for insomnia, depression, or anxiety—offer highly effective, non-medication approaches to improving sleep quality.

10. Caregiver Corner

- Track sleep patterns and share with providers.
- Reinforce routines and morning light.
- Ensure a safe environment for both of you.
- Wind down together—pause, breathe, connect.
- Protect your own sleep, rest is essential for caregiver well-being.

KEY TAKEAWAYS

Sleep problems are common in PD but treatable. Non-drug strategies are powerful first steps toward better rest, brighter days, and improved well-being for both individuals with PD and caregivers.



APDA Strictly Social

Good Times. Great Company



PARKINSON'S SOCIAL EVENT

- Connect with others who understand the Parkinson’s journey
- Enjoy low-pressure, judgment-free environments
- Reconnect with joy, laughter, and new friendships
- Strengthen mental and emotional well-being through social engagement
- Call (708) 329-9527 for more information or **SCAN** to register!

Naperville, IL

PD & Pizza
 1st Tuesday Every Month 6:00 - 7:30 pm
Up North Ale House
 1595 N Aurora Road, Naperville, IL
 Sponsored by: Boston Scientific, Senior Lifestyle, and Supernus

Northbrook, IL

PD & Pizza
 3rd Thursday Every Month 12:00 - 1:00 pm
Barnaby’s of Northbrook
 960 Skokie Blvd.
 Sponsored by: Boston Scientific, Supernus, and HomeWatch Caregivers

Virtual

APDA Strictly Social
Virtual via Zoom!
 2nd Wednesday Every Month
 12:00 - 1:00 pm
In partnership with Shirley Ryan AbilityLab

A PARTNER IN CARE

Carol's Perspective After 55 Years of Marriage



Carol Adamski, of Northern IL, sat down with our Executive Director to reflect on 55 years of marriage, the realities of Parkinson's, and the small practices that help her stay grounded.

When Carol talks about living alongside Parkinson's disease, she gently corrects a word many people use automatically. "I'm not a caregiver," she says. "I'm a partner in care—Lloyd has been able to stay very independent." When asked what title she would give this season of life, Carol smiled and added, "Being married for 55 years is a title in itself."

That steady partnership shapes how Carol navigates daily life with Parkinson's. "I used to think I wouldn't hold back information," she explained. "But I've learned to deliver the right message at the right time." It isn't about avoiding hard truths, it's about choosing the moment in a way that protects dignity and preserves peace.

When asked what no one warned her about, Carol didn't mention the obvious challenges. Instead, she pointed to quieter symptoms that affect confidence and daily routines. "Pain, fatigue, and drooling: those weren't what we expected."

Carol also wanted to dispel a common myth about being a care partner. "People think you should always be helpful," she said. "The truth is, often they don't want help...and that's okay. It gives me time to care for myself." Sometimes, she added, the best thing to do is nothing at all.

When asked for one small but meaningful tip, Carol didn't hesitate: "Patience! Keep working on your patience and try to learn to shake things off." When reflecting on what she's proud of, her answer echoed that same strength: "Patience and avoiding arguments."

What brings her hope? "Research," Carol shared. "New drugs, new

treatments, and a cure." And if she could leave herself a note to read ten years from now? "You did the best you could." Carol emphasized that care partners need to be gentle with themselves and focus on the wins, even amid ongoing challenges.

Carol also spoke about how APDA has supported their journey. "With APDA, we've learned so much, from the experts and from each other," she said. "Everyone's journey is different, and the stages are long, but the programs and events truly help. It's a wonderful community. APDA supports us 100%, and we support them."

5 Care-Partner Tips Inspired by Carol

1. Use language that fits: if "partner in care" feels right, claim it.
2. Share information with intention, and remember that timing matters.
3. Talk about non-motor symptoms can have a big impact.
4. Honor independence and use that time for self-care.
5. Practice patience daily: pause, breathe, and let things go.

Melanie Adams

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EXERCISE CLASS SCHEDULE

Register online at www.apdaparkinson.org/il

ILLINOIS

BREESE

Clinton Co. YMCA

Tues/Thurs 12:30 pm – Exercise for Parkinson’s

CARLINVILLE

Area Hospital

Tuesday 10:00 am – Exercise for Parkinson’s

COLUMBIA

Monroe County YMCA

Mon/Wed 12:05 pm- Exercise for Parkinson

DECATUR

YMCA

Mon/Wed/Fri 11:00 am – Pedaling for Parkinson’s

Tues/Thurs 9:00 am – Parkinson’s on the Move

DOWNTOWN BELLEVILLE

YMCA

Mon/Wed 11:00 am – Exercise for Parkinson’s

EAST BELLEVILLE

YMCA

Tues/Thurs 11:00 am – Exercise for Parkinson’s

EDWARDSVILLE

YMCA

Tues/Thurs 11:00 am – Exercise for Parkinson

HIGHLAND

Korte Rec Center

Mon/Wed/Thurs 11:00 am – Cycle and Strength

O’FALLON

YMCA

Tues/Thurs 12:00 pm – Exercise for Parkinson’s

QUINCY

YMCA

Tues/Fri 10:30 am – Fit to Fight PD Boxing

SPRINGFIELD

Grant Conservatory of Music and Dance

Tues/Thurs 1:30 pm – The Joy of Movement

VIRTUAL VIA ZOOM

Wed 10:30 am – The Joy of Movement

READY TO GET MOVING?



Virtual exercise options make it easy to stay active, build strength, and keep your energy up, all from home. Whether you’re looking for gentle movement or a more energizing workout, there’s something for everyone.

Visit our virtual events calendar to find a class that fits you!

<https://www.apdaparkinson.org/upcoming-events/>



SUPPORT GROUP SCHEDULE

Register online at www.apdaparkinson.org/il

ILLINOIS

ALTON

SSP Main Building, The Meeting Room
2nd Wednesday 1:00 pm

ALTON

SSP Wellness Center
2nd Tuesday 2:00 pm – Care Partners ONLY

AURORA

Waterford Place
1st Tuesday 10:30 am

AURORA

Waterford Place
3rd Tuesday 10:30 am – Care Partners Only

BELLEVILLE

Southwestern Illinois College's
Programs and Services for Older Persons
3rd Monday 1:30 pm

CARBONDALE

Prairie Living at Chautauqua
1st Wednesday 1:00 pm (check with APDA first)

CARLINVILLE

Carlinsville Area Hospital, MOB Comm Rm
4th Tuesday 11:00 am

CENTRALIA

Heritage Woods Independent Living
2nd Wednesday 2:00pm

CHICAGO

Virtual PD Support Group, APDA Information and
Referral Center at University of Chicago
4th Tuesday 11:00 am (group takes summers off)

CHICAGO

Virtual Support Group MEN ONLY, APDA Information
and Referral Center at University of Chicago
1st Tuesday 11:00 am

DECATUR

Westminster Presbyterian Church
3rd Thursday 1:30 pm

EDWARDSVILLE

YMCA Niebur Center
1st Tuesday 2:00 pm

GLEN ELLYN

Movement Revolution
3rd Monday 7:00 pm

GLENVIEW

Endeavor Health Ambulatory Care Center
2nd Tuesday 11:00 am

GREENVILLE

Bond County Senior Center
2nd Tuesday 1:00 pm

HIGHLAND

St. Joseph's Hospital, Sullivan Conf. Rm
4th Wednesday 2:00 pm

JACKSONVILLE

Virtual Group
1st Wednesday 1:00 pm

MAYWOOD

Loyola Outpatient Center
1st Monday 2:00 pm

NORMAL

The Activity Rec. Center (The ARC)
3rd Tuesday 1:00 pm

NORTH UTICA

Utica Fire Station
1st Monday 1:30 pm

NORTHBROOK

Covenant Living of Northbrook
4th Monday 10:00 am

NORTHFIELD

North Shore Senior Center
2nd and 4th Wednesday 2:00 pm

OKAWVILLE

St. Peters UCC Church Hall
1st Tuesday 6:30pm

QUINCY

Quincy Library
2nd Saturday 10:00 am

SPRINGFIELD

Chatham United Methodist Church
4th Friday 1:30 pm

PREPARING FOR MEDICAID

Spend Down and other Myths



Once we start talking about Medicaid we hear terms like Spend Down and look back periods, which are confusing and very often misunderstood.

We will discuss the process, but first we should debunk the two most common myths:

1. Spend Down does not mean you have to spend money on medical care.
2. There are exceptions to the transfer rules. One big exception is that transfers to your spouse are exempt from the five-year transfer rules.

The rules favor a married person. Instead of a Spend Down plan, we like to use the term “financial restructuring.” Once we have determined the value of the assets the community spouse can keep¹, we create a plan to restructure the countable assets that are putting the couple over

the resource limit. The plan may involve paying for medical or long-term care for some short period of time, but it is not required. The plan often involves moving assets out of the countable resource column and into the community spouse’s income column, using a specialized annuity called a single premium immediate annuity.

The look back period is currently set at 60 months before the month in which you would like your Medicaid benefits to begin. Any ineligible gift or sale of any asset for less than fair market value may trigger a penalty period. During this period, you must be otherwise eligible for Medicaid, but benefits will be withheld until the penalty period is exhausted. (This means you are responsible to pay for your own care during that time.) Transfers to spouses are exempt. There are exceptions to the rule, which will allow gifts

without triggering a penalty period, in addition to the spousal exemption.

The key question is: how much can the community spouse keep?

The process of determining this amount is called the attribution process. The state will pick one day in time to look at your financial situation. This is referred to as the attribution date. You will provide a list of all assets held on that day, regardless of whose name the asset is in, as long as one of the couple is listed as an owner. They separate items on this list into countable and non-countable assets. The list of non-countable assets is the shortest: home, one vehicle, personal items, and a few other things, depending on your state.



In most states, your retirement savings account is a countable asset, which often means that you need to liquidate some or all of the account, and pay the taxes triggered by the liquidation. One common mistake is that people have begun spending money before the attribution date. This is counterproductive to preserving assets because the community spouse's resource allowance is directly tied to the amount of assets on the date of attribution. The more savings the couple has on the date of attribution, the more assets the community spouse gets to keep without having to restructure.

Takeaways:

1. If you are married, you can get Medicaid benefits no matter how much money you have (generally). The real question is: is it a good idea? This is largely based on a cost benefit analysis. What are the tax consequences of liquidating assets/what is the monthly financial savings if Medicaid benefits are accessed. This provides you with your break-even point: the number of months after which the savings in medical care outweighs the cost of getting benefits in place.
2. Do not start spending money before your attribution date; consult an experienced elder law attorney to help determine your attribution date and about your options and the timing of your financial restructuring plan.
3. Spend Down does not mean spending money on nursing home care or other medical care. It simply means moving money out of the countable asset column. One way to do that is to convert it to income.
4. There are complicated exceptions to the look back rules that can be used to your best advantage. These are best explained by an experienced elder law attorney.



Cynthia P. Letsch
JD, CMP

Cynthia Letsch is a graduate of Drake University Law School. Her practice is focused on Elder Law, Special Needs Planning, Substitute Decision Making, and Post Death Administration. She will be the Keynote speaker at the Iowa APDA Annual 2026 conference.

¹ The resources the community spouse can keep is 50% of the value of the countable assets existing on the day of attribution, up to the maximum amount. The maximum amount changes each year. For 2026 it is \$162,660.

Giving Highlight

IRA Charitable Gifts: If you're 70½ or older, you can make a qualified charitable distribution (QCD) directly from your IRA to support our work, without increasing your taxable income. It's a simple way to give today while making a meaningful difference. For more information or questions, please reach out to Melanie Adams at: madams@apdaparkinson.org



» UPCOMING EVENTS & PROGRAMS

Chicagoland Optimism Walk

Our largest community celebration! Saturday, **June 20th** at the Naperville Riverwalk.

More details below 

Registration is open!

Concert - DIY Fundraiser

Two bands for one rockin' evening! Performances by both bands, 7th Heaven and Hi Infidelity! Friday, **April 17th** doors open at 6:30 at Joe's Live - 5441 Park Place, Rosemont, IL

Connecting Through Art

This creative and fun program is developed to provide those impacted by Parkinson's disease the space and ability to express feelings and emotions through a creative activity, while also connecting with others who share some of the same challenges and concerns.

April 2026 Northshore Senior Center in Northfield

Parkinson's Education Programs

Education programs for those living with PD and their care partners.

Saturday, March 14th from 10 am - 12 pm
Small Steps, Big Changes: Neurology, Freezing of Gait & Daily Movement

Location: Deerfield, IL

May 2026

Calm the Mind, Support the Body: Holistic Approaches to Parkinson's

Location: To Be Determined

Visit our Upcoming Events & Programs page for details and to stay up to date on everything happening with APDA Illinois.

Go to: <https://bit.ly/ILupcomingevents>



AMERICAN
PARKINSON DISEASE
ASSOCIATION

SAVE THE DATE

2026 Chicagoland Optimism Walk

Saturday, June 20th
9:00 am Check In, 11:30 am Walk Start



Naperville Riverwalk Pavilion
912 Honorary Sindt Memorial Ct., Naperville, IL



apdail@apdaparkinson.org
708-329-9527



Details

**Scan or
Call to
Register**



» TIPS FOR LIVING WELL

HAND STRENGTHENING EXERCISES

Strengthening the hands can help maintain independence with activities of daily living in PD. Working the small muscles of the hands and fingers can help improve fine motor control and hand dexterity, which can translate into improvements in writing.

Here are some Occupational Therapy tips to exercise the muscles of the hands. Perform 10-12 repetitions of these exercises 1-3 times per day to see results:

In-Hand Manipulation:

- Hold an object in the palm of your hand, move it to your fingertips and back to your palm, and repeat

- Hold a round object in your hand and rotate it clockwise and counterclockwise

Finger Isolation:

- Place your palm and fingers flat on a table, lift one finger up at a time, and repeat with all fingers
- Make an “O” by touching your thumb to each of your fingers
- Pick up coins from the table using your thumb and one finger to pinch, and repeat using each finger

Strengthening:

- In the palm of your hand, squeeze an object that has resistance
- Theraputty

- Start with one strength and build your way up as you get stronger
- Stress ball or rolled-up socks can work as well
- Place a small rubber band around two fingers at a time and stretch the band
- Finger Exerciser
- Start with one strength and build your way up as you get stronger



Continue learning about hand strengthening and handwriting in Parkinson’s disease with the APDA Closer Look article by Rebecca Gilbert, MD, Ph. D.: apdaparkinson.org/article/how-to-improve-handwriting-in-parkinsons-disease/




Each issue, we share practical tips, insights, and encouragement to help you navigate your caregiving journey with confidence and care.

Starting Your Year with Resilience


Spring is a season of new beginnings, not just for the person you care for, but for you as a care partner. Take time this season to focus on your emotional well-being.

Pause & Reflect



Start a simple daily journaling habit to track emotions, victories, and challenges.

Stress Breaks



Try 5 to 10 minute mindfulness, breathing exercises, or meditation each day.

Build Your Network



Reach out to local or online support groups to share your experiences and gain advice.



Some days are heavy, and that’s okay. If you need a listening ear or support along the way, please give us a call, we’re here for you.

Remember: caring for yourself allows you to care better for others.

apda AMERICAN
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ILLINOIS CHAPTER

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Naperville, IL 60567-2164

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Two Great Bands, One Great Cause!

ROCK OUT TO KNOCK OUT PARKINSON'S BENEFIT

7th heaven

**HI
HI INFIDELITY**

**JOE'S
Live**

FRIDAY, APRIL 17, 2026

joesliverosemont.com

Net proceeds from ticket sales to be donated to the ADPA Illinois Chapter

TICKETS / INFO

apda AMERICAN PARKINSON DISEASE ASSOCIATION ILLINOIS CHAPTER
Strength in optimism. Hope in progress.

Non-Profit Org.
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PERMIT NO. 1032

Thank you Hi Infidelity and 7th Heaven for hosting an APDA DIY Fundraiser!
Get ready for a great concert on April 17th at 7:00 pm. Location Joe's Live in
Rosemont, IL. Scan the QR code to get your tickets!

Interested in hosting your own DIY fundraiser? Learn more here:
<https://www.apdaparkinson.org/get-involved/diy-fundraising/>

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LET'S CONNECT

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