



**LEWY BODY DEMENTIA**  
R E S O U R C E C E N T E R  
BRINGING AWARENESS, SUPPORTING WITH LOVE

**May, 2020**

Dear LBDRC Friends and Caregivers,

*“Self-care is not selfish. You cannot serve from an empty vessel.”*

Now that we're nearing the end of May, certain routines have become commonplace. We hope the information and links below will help to break up some of the routine and make your time home a bit more focused and enjoyable.

## **ENJOYMENT FROM HOME**

**LINCOLN CENTER FROM HOME** - A Gateway to the Performing Arts is here to provide you and your family with classes, special concerts, and archival performances. They also have new videos every week.

[http://email.wordfly.com/view/?sid=MTQwNF8yMjcwNV8zNjk2MjdfNzE3NA&l=0ab038f2-5586-ea11-bd94-e61f134a8c87&utm\\_source=wordfly&utm\\_medium=email&utm\\_campaign=042720LCatHome%3ANewsletter9\(INTEREST\)&utm\\_content=version\\_A&uid=462777&sourceNumber=16451](http://email.wordfly.com/view/?sid=MTQwNF8yMjcwNV8zNjk2MjdfNzE3NA&l=0ab038f2-5586-ea11-bd94-e61f134a8c87&utm_source=wordfly&utm_medium=email&utm_campaign=042720LCatHome%3ANewsletter9(INTEREST)&utm_content=version_A&uid=462777&sourceNumber=16451)

**TRAVEL: ISRAEL - Eight ways to visit from the comfort of your home**  
- Climb Masada, explore the Western Wall tunnels, and much more:

<https://www.israel21c.org/8-ways-to-visit-israel-from-the-comfort-of-home/>

**NEW YORK CITY BALLET** - Watch a host of excerpts from some of the greatest ballets PLUS dance classes:

[http://email.wordfly.com/view/?sid=MzAyXzI4OTI3XzUwNDA1NV83MDc3&l=06d07dc8-9990-ea11-bd94-e61f134a8c87&utm\\_source=wordfly&utm\\_medium=email&utm\\_campaign=FY20MKACQSpringDigitalBreakfast5&utm\\_content=version\\_A&uid=1445012&promo=46414](http://email.wordfly.com/view/?sid=MzAyXzI4OTI3XzUwNDA1NV83MDc3&l=06d07dc8-9990-ea11-bd94-e61f134a8c87&utm_source=wordfly&utm_medium=email&utm_campaign=FY20MKACQSpringDigitalBreakfast5&utm_content=version_A&uid=1445012&promo=46414)

**BROOKLYN BOTANIC GARDEN** - Cherry Esplanade in Full Bloom - MEDITATIVE WALK: [https://www.bbg.org/news/cherry\\_esplanade\\_walk\\_video](https://www.bbg.org/news/cherry_esplanade_walk_video)

Also, save the date of **Tuesday, June 2**, when **Brooklyn Botanic Garden @ Home** presents their virtual Spring Fling. Join them online to green your mind, body, and spirit with free BBG workshops, classes, and performances during the day.

## EXERCISE AT HOME

**The Parkinson's Foundation offers Fitness Fridays** - As part of their [\*\*PD Health @ Home\*\*](#) program, this free 10-part video series focuses each week on one aspect of fitness designed to support people living with Parkinson's and can be very helpful for people with LBD. Scroll down on this link to find posted 15 minutes videos for different parts of the body: <https://www.parkinson.org/understanding-parkinsons/coronavirus/PD-health-at-home/Fitness-Fridays>

## SURVEY

Are you serving as a caregiver to a loved one during this pandemic? PBS NewsHour wants to hear from you.

Your responses will be shared with PBS NewsHour staff, and they may use them on PBS NewsHour's broadcast, online and social media platforms. A producer or reporter from their team may be in touch with you.

<https://docs.google.com/forms/d/e/1FAIpQLScZe3KYiVEcq0uVnkrZ9QjsvRak45xsfnu-QCDRGRUhBdc6hQ/viewform>

## HELPFUL INFORMATION

***Lewy Body Dementia and the Autonomic Nervous System*** - This insightful article was written by retired psychotherapist and current LBD caregiver, Pamela Rosenblum. It is an issue that affects many people who have LBD and may be very helpful.

<https://lewybodyresourcecenter.org/lewy-body-dementia-and-the-autonomic-nervous-system/>

**GERIATRIC HOUSE CALL DENTISTS** - Alisa Kauffman and her partner, Rachel Klein, make in-home dental visits in Manhattan, Queens, Nassau and Western Suffolk. For information, please see their website at: <https://www.geriatrichousecalldentistry.com/about-dr-kauffman/>

## **PARKER JEWISH INSTITUTE - WILLING HEARTS, HELPFUL HANDS CAREGIVER SUPPORT INITIATIVE - LONG ISLAND**

**Companionship Program** - They offer a companionship program that connects caregivers, who reside in Nassau and Suffolk Counties, with trained volunteers who provide the care and supervision to individuals with Alzheimer's disease or other dementias on a schedule designed to allow caregivers the time, personal space and freedom that is essential for healthy living. All volunteers are interviewed, screened through the State-wide Criminal Background/FBI check and the National Sex Offender Registry, and receive special dementia care training. All of these services are free and are paid for by a multi-year grant from the New York State Department of Health. Please call: 516-586-1507.

**TIPS** to help reduce tensions and strengthen bonds during COVID-19 (from Alzheimer's Foundation of America):

**Identify and understand the triggers.** Knowing what actions generate stress and frustration, both for the person with dementia and yourself is important. Recognizing those triggers early, and reacting to them quickly and constructively, reduces the likelihood of a "blowup."

**Keep a journal.** This will enable you to track your loved one's behavior and triggers, both positive and negative ones, as well as keep tabs on your own. Journaling can be an effective therapeutic tool to release emotions, gain self-knowledge, increase ability to problem-solve, and heal relationships.

**Try to maintain a daily structure.** Routines can help reduce stress and anxiety. If your loved one gets up, eats or goes to sleep at certain times, adhere to that schedule as best as possible. If you normally exercise every morning before work, continue doing so, even if you're not leaving the house.

**Find coping mechanisms.** Meditation, counting to twenty or taking a few deep breaths are all quick and easy ways to calm yourself down and de-stress in the moment. "Venting" or talking things through with trusted loved ones or friends can be helpful.

**Have "family care meetings."** In the case of caring for a family member with dementia, the relative who lives with or nearest to them often provides the majority of the care. This can lead to feelings of resentment. It's important to regularly bring family members together for a "care meeting" to discuss the situation and divide responsibilities, which may include financial and legal duties in addition to personal care. Collaboration, compromise and structure are key to effective family care meetings. These meetings can be held over the phone, and virtually through Zoom, Facetime, Skype, etc.

## **NURSING HOME INFORMATION**

**HOW BEST TO GET INFORMATION ABOUT YOUR LOVED ONE IN A NURSING HOME** - There is no excuse for not getting proper information about your loved one in a nursing home. It is, of course, unacceptable, as well as a violation of Department of Health guidelines. The most effective thing to do is to reach out to the ombudsman at the facility. If you are unable to obtain the name of the person at the facility, you can search for the ombudsman for that particular nursing home at: [aging.ny.gov/long-term-care-ombudsman-program](https://aging.ny.gov/long-term-care-ombudsman-program)

**Is Your Loved One in a Nursing Home? 6 Questions You Need to Ask plus more from AARP:**

<https://www.aarp.org/caregiving/nursing-homes/?fbclid=IwAR12UUcdmtjm8NPvzqOWG1iZB9vq10t43KzSND1HWPb38J-8VPKCul09-dk>

## **PRESENTATION**

Beth Israel Mount Sinai is hosting a training for all Living in Place situations for seniors who want to remain in their own homes to anyone with a minor or major physical disability. Beth Forer is a kitchen and bath designer and renovates entire homes. Her

presentation is about designing the physical space of a home to make it more comfortable and suited to someone's needs: easy to maneuver bathrooms, kitchens, wide hallways and doorways, no-saddle room transitions, adequate lighting, and more for someone whether they may have a tremor, balance issues, needing wheelchair accessibility, etc. Her Zoom presentation on May 27th (3pm) will be approximately 45 minutes, followed by Q&A and an open discussion. To RSVP, those interested can email [Shameeka.kumar@mountsinai.org](mailto:Shameeka.kumar@mountsinai.org)

The Zoom Meeting link

is: <https://mountsinai.zoom.us/j/98867605255> - Meeting ID: 988 6760 5255

**SONG** - "You'll Never Walk Alone" Virtual Choir/Orchestra 15 Countries: 300 People - 3 Minutes

[https://www.youtube.com/watch?v=6gpoJNv5dlQ&feature=emb\\_share&fbclid=IwAR3eIS8v4WFZW8XPW-Xbq28m-Pml0mvVTs\\_n7dgcSX-zsXAPCTWxnDPZXD5](https://www.youtube.com/watch?v=6gpoJNv5dlQ&feature=emb_share&fbclid=IwAR3eIS8v4WFZW8XPW-Xbq28m-Pml0mvVTs_n7dgcSX-zsXAPCTWxnDPZXD5)

Please know we are here for you via phone and email. As a reminder, all support groups will take place via Zoom or conference calls until further notice. They will continue to be led by Ilene Stern for Nassau, Susanne Pargament for Suffolk, Susan Visconti for Westchester, and Norma Loeb, Mary Lou Falcone and/or Laura Kramer for Manhattan. Our helpline is available from 8am to 8pm EST seven days per week at 516-218-2026

Warm regards to all,  
Norma

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