



Seeing Through Lewy

UNDERSTANDING AND MANAGING VISUAL
CHANGES IN LEWY BODY DEMENTIA

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Visual Function in Lewy Body Dementia

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We usually think only of our eyes when we discuss vision. However, 25% of our brain is dedicated to processing vision with another 25% devoted to interacting with the visual regions of our brain to help us create memories, recognize people, objects, and places, perform complex tasks with our hands, find our way, and avoid hazards. When those visual areas of the brain are impacted by Lewy bodies, simple and day-to-day activities can be impacted.

Below we review methods of helping limit the impact of these brain changes in the setting of Lewy bodies and introduce what goes wrong with vision in Lewy body dementia. There is not a “one-size fits all” approach and we often hear from our patients and their care partners what worked for them and what did not. That feedback helped us create this document.



BACKGROUND INFORMATION

From the Eyes to the Brain:

Vision is a complex process that begins in the eyes.

To see what our eyes detect, visual signals from the eye must be sent to the brain. One of the most important regions of the brain that receives information directly from the eyes is a region called the thalamus, which is a structure in the deep center of the brain. From there, information travels to the posterior lobe of the brain called the occipital cortex. The cortex is a special type of brain tissue and regions of the cortex are dedicated to a variety of different functions. For instance, the cortex helps create our memories, interpret and produce language and speech, processes information from the five senses, and helps control voluntary movements. The occipital cortex is an area that is solely dedicated to vision. After it receives visual information from the thalamus, the occipital cortex works to provide feedback to the thalamus to control what visual information we pay attention to, and it also sends information out to other regions of the brain so we can act upon what we are seeing or recognize what we are seeing and compare it to our stored memories. Beyond the cortex, the eyes also send information to our brain stem and an area called the hypothalamus; the vital visual information sent to these regions helps our brain control eye movements, the focusing power of the eye, and the sleep-wake cycle.

Lewy body dementia (LBD): When Lewy body dementia occurs, it tends to impact the visual system by affecting the occipital cortex and the brain stem and interferes with our ability to process and respond to visual information. Visual brain dysfunction can even be the first sign of the disease. Often, visual signs and symptoms early in the disease worsen and the cause remains undetected until the middle or late stages of LBD. Some symptoms, such as visual hallucinations, are easy to recognize as a symptom of LBD and occur early and persist throughout the disease.

Detecting Visual Brain Dysfunction: Testing the basic visual function of the eye and the eye examination do not readily lead to the detection of visual brain dysfunction. Instead, the examiner must be looking specifically for visual brain dysfunction, and those types of tests are not part of the routine eye visit. For example, a common test to evaluate cognitive brain processes that rely on vision includes copying a geometric figure or a clock drawing test.

When either is abnormal, it is a clue that visual brain dysfunction is likely present. Interpretation of a complex visual image or scene can also be part of the assessment for visual brain dysfunction. This type of testing can reveal decreased visual attention, particularly for objects in the left half of a person's vision, or abnormal visual detection of the overall scene. In summary, measuring visual brain dysfunction requires specialized tests and assessments usually administered by a neurologist or a neuropsychologist during cognitive testing.

Impact on Everyday Activity: When visual brain dysfunction is present, there are many everyday activities that become difficult or impossible to perform, particularly when the dysfunction is combined with apraxia, which is the inability to properly perform a task that requires purposeful movements (i.e., dressing or using a smart phone). Although many brain processes are important for driving a vehicle, when visual brain activities are disrupted, driving can be impacted early in the course of disease. A person might have difficulty with parallel parking or hug the line on the road too closely; they might misjudge the speed of oncoming vehicles when turning left at stop lights through oncoming traffic. These are distinctive signs of visual brain dysfunction and are important to recognize for safety reasons.

Supportive Approaches

There are ways that might help compensate for these problems and what works best is unique to each person with Lewy body dementia. Thus, suggestions could work for some but not others or you might find some of your own alternative approaches to help you manage everyday activities. Below we review suggestions to help you offset the impact of visual brain dysfunction due to Lewy body dementia.

SUGGESTIONS TO HELP

3.1 ■ First Steps: Eye Care and Prescription Lenses

One of the first steps to improve visual function in the setting of any type of dementia is to make sure your eyes are as healthy as possible and your prescription lenses are up-to-date and appropriate for the various points of focus you use every day (i.e., distance, mid-range, and near). Some eye doctors might not be aware of how Lewy body dementia can impact vision, but they can provide the type of important eye care health that you need as you age.

General Eye Care

There are many eye changes that occur as we age. Not only is it difficult to focus up close as we age, otherwise known as presbyopia, but our eyes can become dryer and we can develop age-related eye disorders such as cataracts, macular degeneration, and glaucoma. Schedule annual visits to your ophthalmologist even if you think your glasses are the proper prescription because changes can occur inside the eye before you notice the consequence and early treatment can prevent.

Caring For Dry Eye

If a person has parkinsonian motor symptoms, blinking can be infrequent, incomplete, or both. This change in blinking creates dryness of the cornea and visual blurring or even double vision. Use of artificial tears, particularly those without preservatives that come in one-time use vials, can be vital to keeping the moisture level on your cornea adequate. Humidifiers at home in dry climates and staying hydrated are also important to maintaining a good tear film. Keeping your eyelids free of debris by performing lid scrubs daily using water with 1 drop of baby shampoo per cup of water is an important daily routine to keep your oil glands free from dysfunction. To perform a lid scrub, simply wash your eyelids using a soft wash cloth with diluted soapy water. Alternatively, lid scrub kits can be purchased at your local grocery store or pharmacy. Also, ask your eye care provider if any of your medications can increase dryness. Other approaches to treating dry eye are often necessary when it causes persistent blurred vision.

Prescription Lenses

While seeing your eye care provider for prescription lenses, let them know of your diagnosis of Lewy body dementia and that it might impact your ability to use the lenses they prescribe, particularly those lenses that have corrections for different distances within the lens and these include progressive lenses, trifocals, and bifocals. These types of lenses require small eye movements, sometimes combined with slight adjustments in neck position, to get the eyes to be looking through the proper portion of the lens to see things in focus. For those with ocular motor slowing or inaccurate adjustment of the eyes to focus on different distances, these type of multifocal point lenses can be difficult to use.

The eyes can also have a challenging time moving toward each other and when this happens, which is called convergence insufficiency, it can be difficult to read without blur or seeing double. If convergence insufficiency is causing problems with near reading or other near work, the eye care provider might be able to add prisms to your reading lenses to help improve your near vision. For those with Parkinson's disease followed by Lewy body dementia, eye movements often impact the ability to use a multifocal lens for focusing at multiple distances and focusing at nearby. Thus, seeking out proper lenses as soon as visual symptoms become evident when reading or attempting to change focus at different distances is worthwhile.



3.2 ■ Visual Hallucinations

Visual Hallucinations can be a challenging problem to cope with throughout Lewy body dementia. If the visual hallucinations are frightening or if a person is having difficulty recognizing the unreal nature of the hallucinations, the use of medication is an important method of treatment to prevent behavioural changes that lead to disruption or safety issues. Non-medication approaches can be tried even in conjunction with medications and these approaches include the following:

- When hallucinations are frightening, reassure the person they are safe and consider moving to another room
- Increase the lighting and visual and auditory stimulation with activities such as watching a movie or listening to music or books on tape
- Avoid spending extended periods of time in dim lighting or dark rooms other than when asleep
- With the help of the prescribing doctor, eliminate medications that cloud the mind if and whenever possible
- Prevent sleep deprivation with good sleep practices and maintaining the proper day-night schedule
- As noted in the Eye Care and Prescription Lenses section, treat eye conditions, and keep up to date on prescription lenses since poor vision can also lead to visual hallucinations

Many family members and care partners ask whether gently trying to persuade a person that a visual hallucination is not real is the right thing to do when a person believes the hallucination is real. The answer to this is dependent upon the circumstance. If a person is asking for reassurance that what they are seeing is not real, then it is appropriate to comfort the person and help them gain insight that the hallucination is not real.

In other circumstances, a person might be more upset by being told or trying to be convinced that what they see is not real than how they feel about the hallucination itself. As an example, a person might create a story regarding a non-frightening visual hallucination and if they are convinced of the real nature of the hallucination, it might be best to acknowledge the story and simply move on.

In another circumstance, a visual hallucination might be frightening, and it then becomes necessary to make the person feel safe and comfortable and move out of the room or space where the hallucination is being experienced and reassure the person that they are safe and protected. In situations where a person does not feel safe due to recurrent visual hallucinations, medication treatment is the best approach.

In summary, if the act of trying to convince the person with Lewy body dementia that a visual hallucination is not real becomes upsetting for the person or does not provide reassurance or comfort, then it is best to make the person feel safe and consider increasing the lighting, moving to another room, and trying to engage the person in another activity if possible.

3.3 ■ Room Lighting

Visual function in Lewy body dementia can be very dependent on the level of light and the source of lighting. If the room is too bright, it can be difficult to distinguish words on a page or objects from the background. If the room is too dark, the same problem can occur. Find the best light for the task at hand, whether that is eating, watching TV, looking at photos on a phone or other device, looking at a computer monitor, etc.

It is usually somewhere between dim and bright for most people with visual brain dysfunction. The light source is also important. Overhead lighting from can lights can create a glare that makes it difficult to see, but the use of a dimmer can help keep the room well-lit without the brightness that can wash out what is being viewed.

Experiment with different lighting environments during the day and evening by bringing different lamps into a room, opening or closing curtains depending on the time of the day, and changing the brightness of overhead lighting. By increasing the contrast between the background and what you are looking at it will be easier to see. See the section on Contrast.

3.4 ■ Contrast and Electronic Devices

On nearly all electronic devices, the level of contrast for text and images can be adjusted. To determine how to do so, you can search the internet for your device and type "how to change contrast." Once you can adjust the contrast, you can try various levels, but the best for most with visual brain dysfunction is to have the contrast at the greatest level possible, often listed as 100% on devices.

The brightness of text can also be adjusted and the brightness that you want will depend on the background. If the background is white, the brighter the text or image, the harder it is to see because it will blend in with the background. If the background is black, the brighter image will be easier to see. The best way to determine what is right for the person with Lewy body dementia is to experiment. In general, increasing the contrast from what is being viewed and the background will be one way to improve visual function.

This is also important to consider in the environment as well. Avoid flooring that has grey upon grey or white upon white when adding an area rug to a carpet or flooring. These items can become hazards as they will blend into the background and not be able to be seen, contributing to tripping hazards and potentially causing falls.

3.5 ■ Finding and Seeing Items

Many people with Lewy body dementia are not able to find items that are directly in sight or in plain view. At other times, the smallest piece of paper or a very small item can easily be seen. We now understand that the visual brain in people with Lewy body dementia can miss seeing an item when it is within a cluttered environment or when it is mixed in with a lot of other items, such as trying to find a hairbrush on a dresser or bathroom counter that is filled with other items or even a fork on a dining room table.

A key to helping to compensate for this problem is to simplify and de-clutter the environment. There are other qualities of vision changes in Lewy body dementia that make it impossible to interpret the visual stimulus or information, and novel ways of achieving everyday tasks or gathering information must be used to be successful.

To find everyday items:

- Place only the essential items for everyday use in view on counters, on dressers, and in bathrooms and separate items in an organized way.
- Add brightly colored tape to items used every day if they become difficult to find even when they are in a de-cluttered and organized environment. For example, hot and cold-water faucet labels.
- Dimensional Fabric Paint: Paint that dries to a 3-dimensional configuration (i.e., a large, thick dot) is available in many colors and comes in easy-squeeze bottles so they are user friendly. This can be used by placing a DOT on anything from the 30 second setting on a microwave to anything that you commonly use around the house so that it makes it easier to identify. This type of paint can be purchased at any craft store and even hardware stores and online stores.
- Keep items in the same place and when you find them out-of-place be sure to let everyone know you are putting it "back" in its proper place. Many people with visual brain dysfunction find it frustrating when other people move items, even if it is moved to keep things organized. So, always communicate about organizing and when moving an item. Find convenient locations to keep items where you use them. For instance, always keep glasses in one location or in a special, easy-to-see container (e.g., place glasses in a bright blue box on the table near where you read) and try to always put them back in that location.
- Use high contrast placemats or coasters to highlight where items can be placed on tables or nightstands.

Tips for mealtimes:

- Use bright coloured contrasting dishes and ensure they are all one solid color.
- Use a contrasting placemat from your dishware.
- Create contrast from the food to the dish; Light-coloured food will be easier to see on a solid dark-coloured dish, etc.
- Avoid patterned table clothes.
- Maintain a consistent pattern for mealtime set-up. For example, always place the same utensils, drinking glass and condiments in the same place for every meal.
- Avoid cluttering the eating area and only have necessary items within reach.
- Use contrasting plate guards during meal times.

Managing medications:

- Medication supervision is something that should be established early since pills can look the same and be difficult to take on schedule even when pills are in a pill container labeled by the day. An option to consider is the use of one container for each day instead of a container that has one week or more supplied in separate sections.
- Work with your prescribing doctor to try to simplify medication routines (use of long-acting medications that can be taken daily or eliminating medications started years ago but might not be needed as frequently or at all).

To help support reading activities:

Reading material:

Often, even in the early stages, reading can be very difficult. For those who can still read by struggle, a few ideas to prolong the skill of reading include the following:

- Large print with strong contrast (described in Contrast section) might be helpful.
- Clear away any other items from the surface you are reading.
- Avoid printed material on glossy pages, which can be very difficult to read for people with visual brain dysfunction.
- Use a line magnifier, a ruler or other similar item to help move from line to line (it might take some practice).
- Avoid trying to read a page with a lot of different sections and paragraphs and photos (e.g. front page of a newspaper) because this can be confusing to the visual brain that is not fully functional – and to eliminate this problem, consider downloading one article at a time to print off or cut the article out of the newspaper.

Audio instead of reading:

Of course, there will come a time when audiobooks will be the best alternative. The National [Federation of the Blind](#) offers access to national newspapers, including the Wall Street Journal and USA Today and other deliverables. They state on their web pages that "Anyone who cannot read printed publications due to vision loss, dyslexia, or a physical disability is eligible to receive NFB-NEWSLINE."

- You can register by calling your state's Library for the Blind and Physically Handicapped or the National Federation of the Blind at 866-504-7300 to request an application. You may also download and mail an application or complete their online application.
- The benefits include access to news sources, including CNN, BBC, and ESPN. Online and international newspapers, including Financial Times and Vancouver Sun and magazines, including Time, Consumer Reports, Guideposts, and Smithsonian, state newspapers, emergency weather alerts and seven-day forecasts localized to your zip code or GPS location as well as access to the National Federation for the Blind's national channel.
- Overall, observe what is the most frustrating or the most difficult to do and try to find ways to increase contrast and increase ease of performing a task from the perspective of asking... "Could the problem be with visual perception?"

Focus on the ideas that you believe will make the biggest impact and then try it. Invite a family member or friend or grandchild to help you implement them. Others often have ideas that are creative and uniquely suited to the individual with Lewy body dementia.

Set up the environment for success:

- Store/relocate frequently used items at accessible and visible level.
- Keep surfaces and counters clear to minimize clutter.
- Consider goose neck or adjustable lamps to allow for direct lighting of a task.
- Areas and rooms: Set aside areas of a room or areas within the house where certain items will always be and/or activities will take place. So, depending on a person's hobby or interest, create a reading area or an area to view photo albums, an area to craft, an area to tinker or fix items, a tv watching area, a music listening area, etc. Create the area so that it has all the items you need to do the activity.
- To help with telling time: Even in the early stages, the use of an analog or digital watch can be difficult to use. Some find that the use of a low vision talking watch can be quite helpful; there are many brands and styles to choose from and some are inexpensive and simply give the time when a button is pushed. Others can add recorded reminders or give the time at specified intervals. In fact, exploring the world of items for the low-sighted might lead to useful devices to help in everyday activities. Since most of the items were designed for vision loss related to eye disease and not for people with dementia or cognitive impairment, they do not always provide the type of support that is necessary, but they are worth exploring. At the end of this document is a list of smart phone or tablet applications for electronic devices for the blind or low-sighted that are worth exploring.
- Overall approach:
 - Observe what is the most frustrating or the most difficult to do and try to find ways to increase contrast and increase ease of performing a task from the perspective of asking... "Could the problem be with visual perception?"
 - Focus on the idea that you believe will make the biggest impact and then try it. Invite a family member or friend or grandchild to help you implement them. Others often have ideas that are creative and uniquely suited to the individual with Lewy body dementia.

3.6 ■ Getting Dressed with Less Frustration

Keeping closets organized and minimizing the number of clothing items in closets and drawers is the first step in making getting dressed easier. If necessary, you can add specific and very simply signs or labels on a drawer or in the closet as reminders of what items to expect in a specific location.

To help locate clothing items:

- Eliminate clothes not worn frequently so that closets and drawers have fewer pieces of clothing. Put into storage any items that are out of season.
- Organize closets into sections. For instance, separate shirts from tops and from pants and accessories. Alternatively, some people have learned that creating outfits and placing each outfit on one hanger (i.e., an entire outfit on a hanger including the accessories) in the closet so that you can pull out one hanger and not have to search for items can be extremely helpful.
- Organize clothing drawers in a similar manner to closets and some people have found that having a photograph or other label placed on the drawer is useful. Similar labeling can be used in any room where it helps limit frustration when looking for an item.

To help orient clothing items and get dressed:

The next step where vision processing can break down is in orientation of the garment. People with LBD may experience difficulty seeing where the back or the top of a piece of clothing is or perceiving the right from the left sleeve or left from right pant leg.

- Try using a safety pin where the tag is on the back of a piece of clothing, or at the bottom of one sleeve, to decrease frustration of putting on a piece of clothing.
- The use of clothing without buttons or zippers when they become difficult to use is also helpful, although for some people the buttons and zippers help them understand how to orient the clothing item when putting it on.
- Some people report that putting out an outfit for each day in a specific manner (face down on the bed, for instance) or keeping an entire outfit on one hanger after items are washed is extremely helpful.
- Trying to “re-learn” how to dress as one used to do is most often not helpful nor is it possible. Instead, creating a “new” way to get dressed usually takes trial and error and then with progression of dementia, innovative approaches become necessary.

- Consider asking your physician for a referral to an occupational therapist to help find the approaches that work best for you.

3.7 ■ Finding Your Way, Not Getting Lost, Staying Safe

Wandering and getting lost are common for people with brain dysfunction affecting the visual areas of the brain; these visual areas help create the maps that are stored in your memory and if there is difficulty using vision to gain access to these memories, wandering and getting lost can be a concern for safety. Some people report that their loved one with Lewy body dementia was at one moment at their side and then gone the next, especially in a new location (e.g., at a store with which they are not familiar). Even getting from one location to another in the house can become difficult. Some ways that have helped others are listed below.

Tips for navigating outside the home:

- Walking through a grocery store or going for a walk outside can be difficult with visual brain dysfunction. The family member or care partner who accompanies the person with Lewy body dementia can choose to wear a distinctive hat or shirt to help a person follow them or keep them in sight. For instance, a bright color or always choose the same color when outside. Discuss the distinctive piece of clothing before leaving the house and then again when outside as a reminder.
- People with severe visual brain dysfunction can choose to use a cane for the blind and low sighted (i.e., white cane with red tip) to help detect changing slopes of the ground or other objects in the way. Even if the cane is not needed to avoid objects, the use of the cane can alert people to move out of the way and allow one to be recognized as visually challenged. This is strongly recommended for a person who prefers to be more independent but cannot always negotiate new spaces when outside the home.
- Most canes use a telescoping mechanism that allows them to elongate and shorten easily to be put into use and put away quickly. These canes are offered for free from a variety of different local and national associations. One option is the National Federation of the Blind and the link is here for the application: <https://freecane.nfb.org/>. It is important to consult with a physical therapist familiar with Lewy body dementia before purchasing a device to support mobility, and work with that PT to ensure you are able to use the device correctly and safely.

- For walking independently outside the home when that is still possible, routes should be created ahead of time with major markers of the route identified before the walk and reviewed carefully before the walk. For instance, many people want to enjoy a walk around the neighborhood for exercise and do so alone. When this is still possible and safe to do without getting lost, exploring a route with the person with Lewy body dementia so that the route identifiers (e.g., large blue house is where you turn to go around the block) are identified and practiced in advance of attempting to do this independently to ensure safety is important. This typically is not possible once a person is past the middle stages of Lewy body dementia, but every person is different.
- Dogs and service animals: Obtaining and training a service animal can be a lengthy process and most programs require a person to be confident in orientation and mobility skills and be able to navigate a minimum number of routes independently. Furthermore, one safety concern is getting tangled up with leashes and other devices used to harness the animal can lead to falls. We have experienced this with several patients who report a fall when walking their own dog. In summary, guide animals are not usually trained to be helpful for a person with dementia and visual brain dysfunction who wishes to walk more independently outside the home. This does not preclude having a service animal within the home, which can be trained by a family member.



Tips for navigating inside the home:

- Place a sign with an arrow pointing in the direction of an important room (e.g., the bathroom) on a path that creates confusion for the person with Lewy body dementia.
- Consider creative ways to highlight certain rooms (door frames painted a distinct color or pictures or signs on doors).
- Create unique pathways so that every hallway or path does not look the same. You can do so with adhesive tape on floor/or carpet tape – but be careful not to create tripping hazards.
- Stairways can be hazardous for people who have difficulty judging depth and contrast. There are many safety adjustments that can be made such as railings that extend past the top and bottom of the first step and brighten the path to the stairway and on the stairway. Install secure railings on at least one if not both sides of the stairway.
- For those with severe brain dysfunction a stairway might not reveal the same depth that it once had or even look like a stairway. To prevent falls down steps or stairs, install a gait or other safety barrier that alerts a person to the step or stairs.
- Apply contrasting coloured tape or paint on the edge of each step.
- Ask your physician for a referral to physical and occupational therapy to address your home safety concerns and to prevent falls.





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