

A photograph of an elderly woman with short grey hair and glasses, wearing a light green t-shirt, sitting in a wheelchair. She is smiling and looking towards the right. A caregiver in a light-colored uniform stands behind her, with hands on her shoulders. The background is a bright, indoor setting, possibly a care home.

Lewy Body Dementia A Complete Guide

Trevor Howitt
www.readementia.com

Table Of Contents

| | |
|---|----|
| Signs and Symptoms of Lewy Body Dementia | 3 |
| Causes of Lewy Body Dementia | 4 |
| Risk Factors | 5 |
| Stages of Lewy Body Dementia | 5 |
| Diagnosis | 6 |
| Treatment Options for Lewy Body Dementia | 8 |
| Other Considerations | 10 |
| Therapies | 10 |
| Home and Lifestyle Remedies | 11 |
| Non-Drug Approaches | 11 |
| When to See a Lewy Body Dementia Specialist | 12 |
| Prognosis | 13 |
| Coping With Lewy Body Dementia | 13 |
| Tips for Caregivers | 15 |
| On-Going Research about Lewy Body Dementia | 17 |

Lewy Body Dementia - A Complete Guide

Also known as dementia with Lewy bodies, Lewy Body dementia (LBD) is a progressive illness that involves abnormal deposits of a protein known as alpha-synuclein in the brain.

These deposits are referred to as Lewy bodies.

They got their name from [Friedrich H. Lewy](#), the scientist behind their discovery. Lewy bodies grow in the brain's nerve cells affecting thinking and motor control.

It is the second-most common type of dementia after AD ([Alzheimer's disease](#)). Lewy bodies affect different regions in the brain such as:

- **The Cerebral Cortex:** It is the part of the brain that controls multiple functions including perception, information processing, language, and thought.
- **The Limbic Cortex:** It plays a primary role in behavior and emotions
- **The Midbrain and Basal Ganglia:** These play a major role in movement.
- **The Hippocampus:** This is vital for forming new memories.
- **The Brain Stem:** It is essential for maintaining alertness and regulating [sleep](#).
- Sections of the brain important in identifying smells.

It is estimated that about 1.4 million people in America have dementia with Lewy bodies. The number, however, could be more because there are many cases that go undiagnosed.

Keep reading to uncover more essential details about LBD.

Signs and Symptoms of Lewy Body Dementia

Persons who have LBD may experience several [symptoms](#) such as:

Visual Hallucinations

[Hallucinations](#) are among the first symptoms that re-occur in individuals who have this kind of dementia. It can include seeing people, animals, or shapes that are not there. Tactile (touch), auditory (sound), and olfactory (smell) hallucinations are also possible.

Poor Regulation of Body Functions

Poor regulation of the autonomic nervous system is common in persons with dementia with Lewy bodies. Pulse, [blood pressure](#), the digestive process, and sweating are all regulated by a section of the nervous system that is affected by this type of dementia. This can cause falls, dizziness, excessive sweating, and bowel problems like constipation.

Cognitive Problems

Cognitive issues similar to those of Alzheimer's disease are among the warning signs of dementia with Lewy bodies. These can include problems such as poor attention, confusion, [memory loss](#), and visual-spatial issues.

Movement Disorders

Some persons with LBD will experience signs of [Parkinson's disease](#) like rigid muscles, slowed movement, shuffling walk, or tremor which can increase the risk of falls.

Other common movement problems include loss of coordination, balance issue, smaller handwriting, a weak voice, and reduced facial expressions.

Sleep Challenges

Affected individuals may go through rapid eye movement (REM) and sleep behavior disorders which can make them physically act out their dreams as they sleep. Restless leg syndrome, insomnia, and excessive daytime sleepiness are additional sleep disorders that persons with LBD may experience.

Fluctuating Attention

Long periods of staring into space, drowsiness episodes, disorganized speech, and long naps during the day are other possible symptoms.

Depression

In the course of the progressive disease, some persons may experience [depression](#).

Apathy

Most people with this illness will suffer loss of motivation.

Other Symptoms

Persons with LBD may also experience fainting, dizziness, sensitivity to cold and heat, poor sense of smell, urinary incontinence, and sexual dysfunction.

Causes of Lewy Body Dementia

The [origin](#) of dementia with Lewy bodies has not yet been identified. Hallmarks for dementia with Lewy bodies include an abnormal build-up of proteins. These proteins are known as Lewy bodies. They are the same proteins that are associated with Parkinson's disease, another type of dementia.

Lewy Body Dementia - A Complete Guide

Persons with Lewy bodies also have tangles and plaques that are linked with Alzheimer's in their brains. Experts are not sure what causes the build-up of proteins. A majority of individuals who have Lewy bodies do not have a family history of the illness.

To date, scientists have not identified a genetic cause.

Risk Factors

Several [factors](#) are said to increase the risk of developing LBD like:

- **Age:** Persons who have celebrated their 60th birthday are at a higher risk.
- **Sex:** Research shows that dementia with Lewy bodies affect more males than females.
- **Family History:** Persons who have family members with this progressive disease or Parkinson's disease are normally at greater risk.
- **Diseases:** Some health conditions and diseases like REM sleep behavior disorder are linked to a higher risk of dementia with Lewy bodies.

Stages of Lewy Body Dementia

LBD can be distinguished by [3 stages](#) as described below.

Early Stages

The [earlier stages](#) of dementia with Lewy bodies usually involve hallucinations and other reality distortions such as restlessness, delusions, some movement difficulties, and acting out dreams when a person is sleeping.

Some people will appear to get stuck or "freeze" when moving around. Although rare, some individuals will also develop incontinence and urinary urgency during this stage. Some mild cognitive changes and confusion may also be present.

Lewy Body Dementia - A Complete Guide

Middle Stages

As the illness progresses to the middle stages, the symptoms a person experiences begin to resemble those that exist in Parkinson's disease.

These include increased body motor function impairment, frequent falls, challenges with speech, more pronounced delusions and paranoia, and difficulties when swallowing.

Cognition will also continue to decline to include long periods of confusion and decreased attention.

Later Stages

During the later stages of this illness, a person may experience extreme sensitivity to touch and muscle rigidity.

Speech also becomes challenging where it may be absent or a person will communicate with whispers. At this point, care becomes necessary for daily living activities.

Diagnosis

There are 2 possible [diagnoses](#) of LBD. One is dementia with Lewy bodies, and the other is Parkinson's disease dementia.

While the earliest warning signs for both diseases differ, they reflect similar biological changes in the brain. Over time, persons with Parkinson's disease or dementia with Lewy bodies may experience similar symptoms. The diagnosis of dementia with Lewy bodies is quite a challenging process.

Lewy Body Dementia - A Complete Guide

Even so, accurate and early diagnosis is essential. Unfortunately, misdiagnosis as other forms of dementia or as a psychiatric disorder is quite common. There is still no single test that can diagnose the progressive illness.

Doctors, diagnose the condition mostly by ruling out other medical conditions that cause similar symptoms and signs. Some of the tests that physicians conduct include:

Brain Scans

Doctors may order CR or MRI scans to identify bleeding or strokes that rule out the existence of tumors. The imaging studies can help in the identification of various types of dementias like LBD and Alzheimer's.

If the diagnosis is not clear from these tests, physicians may order other imaging tests like fluorodeoxyglucose PET brain scans to assess the function of the brain. SPECT (single-photon emission computerized tomography) or PET imaging can also help determine whether the uptake of dopamine transporter has been reduced in the brain.

Physical and Neurological Examinations

Doctors normally start by checking for signs of strokes, Parkinson's disease, tumors, and other medical conditions that can affect physical and brain function. Neurological **examinations** may test reflexes, walking, strengths, balance, muscle tone, sense of touch, and eye movements.

Mental Abilities Assessment

Doctors may also assess a person's thinking and memory skills. These can help to identify LBD by distinguishing it from Alzheimer's disease. At times, doctors will compare test results with people from similar age-group and education level. This can assist in the diagnosis process as it helps differentiate abnormal and normal cognitive aging.

Lewy Body Dementia - A Complete Guide

Blood Tests

These are conducted to rule out physical problems that may affect the function of the brain. These include underactive thyroid gland and [vitamin B12](#).

Heart Test

Doctors may also order myocardial scintigraphy a heart test that checks blood flow to the heart which can be a warning sign for dementia with Lewy bodies.

Physicians may order sleep evaluations when they want to check for REM sleep behavior. An Autonomic function test might also help for signs of blood pressure and heart rate instability.

For a diagnosis of Lewy body dementia, a person must have at least 2 of these:

- Visual hallucinations
- Fluctuation in cognitive function
- Parkinson's disease warning signs like muscle stiffness and tremor

Treatment Options for Lewy Body Dementia

[Treatment for dementia with Lewy bodies](#) is not easy because there is still no cure for the progressive disease. Most of the time, doctors will try and treat individual symptoms through a variety of options such as:

Medications

Certain medications can be prescribed to persons who have LBD. Research shows that persons who have this progressive illness are sensitive to medication.

It is; therefore, important for medications to be prescribed with caution and careful monitoring. Some of the drugs include:

Lewy Body Dementia - A Complete Guide

Cholinesterase inhibitors

These are Alzheimer's drugs like donepezil, rivastigmine, and galantamine. They are believed to help increase the levels of chemical messengers that are vital for memory, judgment, and thought in the brain.

It can help enhance cognition, alertness, and reduce hallucinations as well as other behavioral issues.

Parkinson's disease Drugs

Medications like carbidopa-levodopa (Duopa, Sinemet, Rytary) might help to reduce some of the signs and symptoms of Parkinson's disease. These include slow movement and rigid muscles.

Medicine for other Symptoms

Physicians may also prescribe drugs that treat other symptoms associated with the progressive illness like movement or sleep issues. People who experience sleep disturbances can get melatonin and low-dose clonazepam.

Other drugs can be used to treat blood pressure and any other symptoms that a person may have.

According to NIH, persons who have LBD may have severe side effects from taking antipsychotics which are medicines used to treat agitation, hallucinations, and delusions.

The reactions can include worsened Parkinsonism, increased confusion, low blood pressure, and extreme sleepiness. Medicines to avoid include risperidone and olanzapine.

If a person with the progressive illness is on antipsychotics, they need to be monitored closely so that they can stop taking the medication as soon as the adverse side effects kick in.

Other Considerations

Doctors may also recommend other measures to help persons with Lewy body dementia. These include elastic stockings and leg elevation for individuals who are prone to falls. If need be, physicians will advise a person to increase their fluid and salt uptake.

It is important to note that taking medication may have side effects. The persons with the disease should talk to their doctors if they get any negative reactions from the drugs prescribed.

Therapies

Several alternative therapies can help persons who have Lewy body dementia.

- **Massage Therapy:** It helps to improve blood flow and enhance relaxation.
- **Music and Art Therapy:** This can help to improve mood and ease anxiety.
- **Pet Therapy:** Pets can help to boost mood and provide companionship.
- **Speech Therapy:** It helps to improve problems with speaking and swallowing.
- **Aromatherapy:** The use of essential oils for therapy can help to soothe and calm.
- **Physical Therapy:** It can help to improve flexibility, strength, gait, and overall health.
- **Occupational Therapy:** This helps to make daily tasks like bathing and eating easier so that they can be more independent.
- **Mental Health Counselling:** Counselling can help both persons with LBD and their relatives or friends learn to cope with all the changes happening because of the illness.

Home and Lifestyle Remedies

Persons who have Lewy body dementia may also benefit from a couple of lifestyle and home remedies including:

- **Physical Exercise:** The perks of [exercise](#) are vast including improving physical function, depression, and behavioral symptoms. Some research also shows that exercise might slow cognitive decline.
- **Mental Stimulation Activities:** Taking part in crossword puzzles, games, and other activities that involve the use of thinking skills can help slow mental decline.

Non-Drug Approaches

Other steps can be taken to help people suffering from dementia with Lewy bodies such as

Modifying Living Environment

Reducing distracting noise and clutter can help individuals with this type of dementia to function better.

Tolerating Behavior

Persons who are close to individuals with the progressive disease should learn how to tolerate their behavior. Most people with the illness will experience a range of emotions like fear, confusion, anger, frustration, depression, grief, and uncertainty.

This is because it is the illness that causes patients to behave the way they do. Offering support and reassurance helps affected individuals retain their self-respect and dignity.

Creating Daily Routines

Most people with dementia will cope better when they follow routines. It also helps to keep the tasks of the affected individuals simple by breaking them into small steps and focusing on successes rather than failures.

It is advisable to offer soothing responses when handling persons with LBD. Avoid quizzing and always correcting persons with this kind of dementia. It is best to offer validation and reassurance for their concerns.

When to See a Lewy Body Dementia Specialist

If a person suspects that they have LBD, the first stop they make is to their primary caregiver. The physician will want to know the symptoms a person is experiencing before referring them to an [LBD specialist](#).

To prepare for an appointment it is advisable to plan and write a list of important details like:

- A detailed description of all the symptoms a person is experiencing
- A list of medical conditions that an individual may have as well as medical history
- A list of all medications, supplements, or vitamins a person is taking
- Questions and concerns to share with the professional

In most cases, the doctors who diagnose and recognize Lewy body dementia are expert neurologists who specialize in dementia and movement disorders.

Geriatric psychiatrists and geriatricians can also identify the progressive disease.

Prognosis

The prognosis is different for individuals who are affected by dementia with Lewy bodies. It can be influenced by the existence of another medical condition, general health, age, and severity of symptoms.

Because the disease progresses at unpredictable rates for each person, it may not be possible to pinpoint how long an individual will live with the disease. Some people may live for over 20 years while others will not survive more than 5 years after the onset of the symptoms.

Research suggests that most people will live for around 5-8 years with the progressive illness. Most people will die from several complications like poor nutrition, falls, immobility, pneumonia, or swallowing difficulties.

Coping With Lewy Body Dementia

Getting a positive diagnosis of dementia with Lewy bodies can be quite challenging for anyone. A person who is having a hard time accepting the situation may have to go through counseling to help them cope with the diagnosis.

Other steps that people can take to live with the illness day to day include

Getting Help

The affected person may want to share their diagnosis with close family and friends. This allows them to understand the changes that a person is going through so that they can offer the support the individual needs.

A support team is important in the life of a person who has LBD. This is because as the illness progresses, it may become difficult to manage daily tasks like paying bills, taking medication, grooming, and driving.

Lewy Body Dementia - A Complete Guide

Help from friends, relatives, and professional caregivers come in handy. Finding local support groups can also help a person meet others who are in the same situation and they can help each other forge ahead.

Pay Attention to Safety

Changes in movement and thinking that occur with the illness requires a person to consider safety. Some of the measures a person can take include carrying an LBD medical alert wallet.

This is usually presented any time a person meets with their doctors, required emergency medical care, or has been hospitalized. The card contains essential details about medication sensitivities and can help save a life.

It is advisable for affected individuals to subscribe to a medical alert service. This way, a push of a button on a necklace or bracelet will help them access 911 for emergency help. Driving skills of a person with the illness should be evaluated to know if it is safe for them to be on the road with the condition.

It is also important to address safety issues at home. This includes getting rid of things that can increase a person's risk of falling. Home modifications like installing grab bars in the bathroom may be beneficial. Doctors can refer persons to home health agencies that [evaluate home safety](#).

Planning for the Future

This has the best impact during the early stages of the disease when a person is of sound mind to make decisions about their lives. It includes consulting financial and legal experts about planning for retirement or disability leave.

Lewy Body Dementia - A Complete Guide

Working with an attorney is also important to help update or write important documents like healthcare power of attorney, and wills. A person can also identify local resources for meals, homecare, and other essential services.

This way, when the time comes, there will be no complications. It may also be important to explore moving to continue care communities when it is no longer safe or practical or safe to stay at home.

Find Something to Enjoy Daily

The attitude a person has when living with Lewy body dementia can make a huge difference. Despite all the adjustments and changes happening, a person should find time to enjoy something daily.

This can be anything from spending time with loved ones, doing appropriate exercises, listening to music, dancing, or participating in any other enjoyable activity.

Tips for Caregivers

The role of a caregiver is bound to become more important as Lewy body dementia progresses. While the situation is different for everyone, here are some tips that caregivers can work with to offer affected individuals the support they need.

Effective Communication

Caregivers should speak slowly in a clear voice using simple sentences. Pointing and hand gestures can also help. Give the person time to respond and avoid offering too many options as this may lead to increased confusion.

Understand that the disease may cause a person to experience a wide range of emotions; thus, carers need to be reassuring, non-judgmental, and respectful.

Lewy Body Dementia - A Complete Guide



Offer Physical and Mental Stimulation

Simple exercises and stretching routines are good for persons with LBD. Being physically active during the day can promote better sleep at night.

It is also good to keep affected persons busy with mentally stimulating activities like games and puzzles that require thinking skills.

Care for the Caregiver

It is not easy looking after someone who has dementia with Lewy bodies. Caregivers also need to look after themselves so that they can offer the best care to the person they are looking after.

Some self-care tips include asking for help from other professionals or friends and family members when things get overwhelming. Taking time off to spend quality “me” time helps a person to get in the right frame of mind.

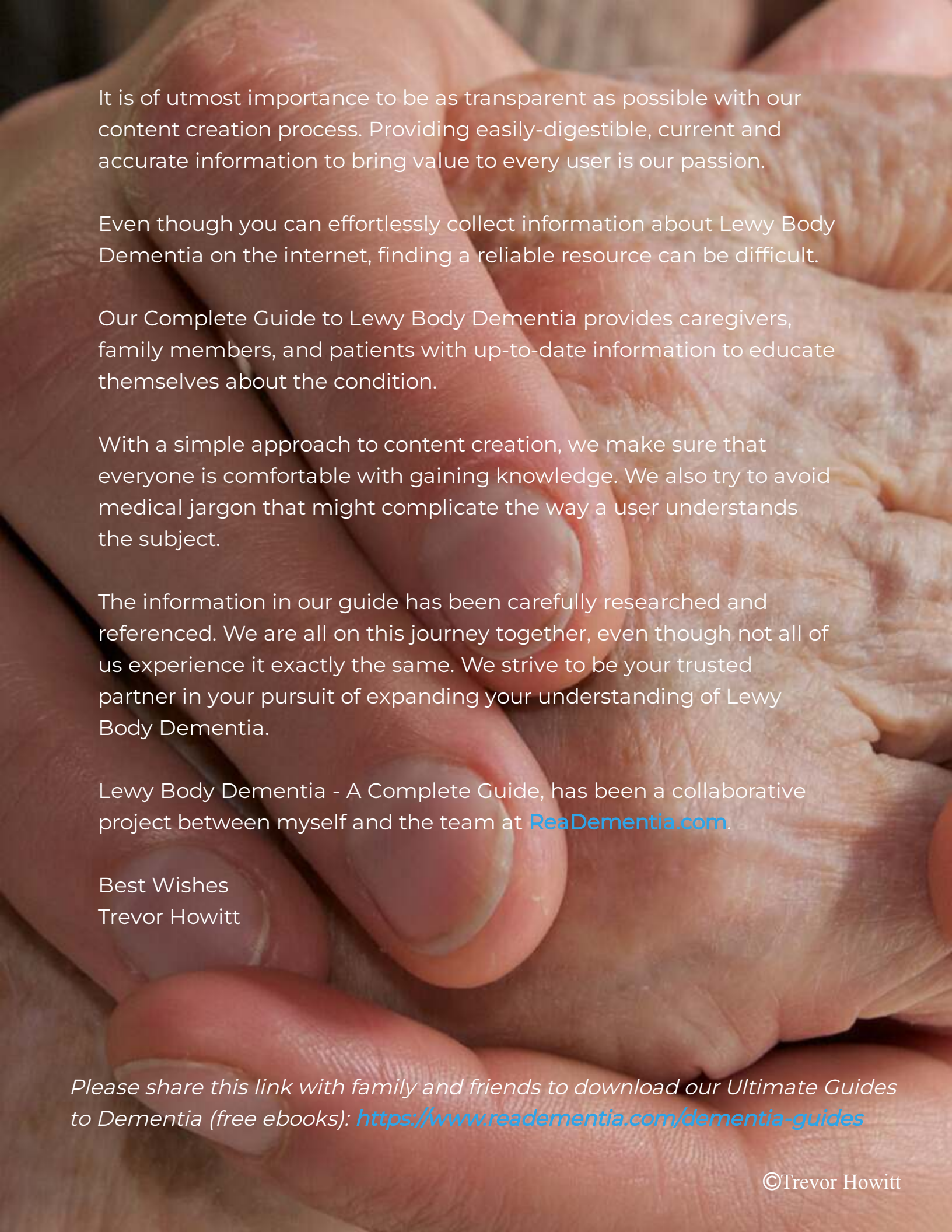
Eating right, working out, medication, and consulting a doctor can help the caregiver remain in tip-top condition.

On-Going Research about Lewy Body Dementia

There is still a lot to learn about LBD. Scientists are still trying to figure out what causes the progressive illness. Most research avenues focus on offering a better understanding of dementia with Lewy bodies.

Some researchers are looking to identify the specific differences in the brain between Parkinson's disease and LBD. Others are working on getting more information about the genetics, underlying biology, and environmental risk factors of the disease.

Several professionals are also trying to pinpoint biomarkers of the disease in a bid to enhance screening tests that may help in diagnosis, new effective treatments, and ways to prevent and cure the disease.



It is of utmost importance to be as transparent as possible with our content creation process. Providing easily-digestible, current and accurate information to bring value to every user is our passion.

Even though you can effortlessly collect information about Lewy Body Dementia on the internet, finding a reliable resource can be difficult.

Our Complete Guide to Lewy Body Dementia provides caregivers, family members, and patients with up-to-date information to educate themselves about the condition.

With a simple approach to content creation, we make sure that everyone is comfortable with gaining knowledge. We also try to avoid medical jargon that might complicate the way a user understands the subject.

The information in our guide has been carefully researched and referenced. We are all on this journey together, even though not all of us experience it exactly the same. We strive to be your trusted partner in your pursuit of expanding your understanding of Lewy Body Dementia.

Lewy Body Dementia - A Complete Guide, has been a collaborative project between myself and the team at [ReaDementia.com](https://www.readementia.com).

Best Wishes
Trevor Howitt

Please share this link with family and friends to download our Ultimate Guides to Dementia (free ebooks): <https://www.readementia.com/dementia-guides>