



# The Role of Palliative and Hospice Care in Lewy Body Dementia

## INTRODUCTION

Lewy Body Dementia (LBD) is a progressive neurodegenerative disease with cognitive, motor, sleep, and behavioral symptoms. Because these symptoms are similar to those of Alzheimer's and Parkinson's disease, it can take some time to correctly diagnose LBD. Once the diagnosis has been made, families go through a process of adjustment as they come to understand more about LBD symptoms and treatments and as they try to anticipate what the future will hold. Because there is no cure, it is important for families and physicians to focus on helping people with LBD maintain the highest possible quality of life. In addition, families need emotional support and guidance in their roles as caregivers and advocates. Palliative care and hospice programs have an important place in helping families to achieve these goals.

## WHAT IS PALLIATIVE CARE?

The goal of palliative medicine is to improve quality of life by relieving the symptoms of disease. Accepting palliative care services does not mean that someone has given up hope of a cure. Instead, it signifies recognition that the quality of one's life is as important as its duration. Generally speaking, palliative care can benefit people of any age at any stage of illness, whether that illness is curable, chronic, or life-threatening. For example, patients with cancer, multiple sclerosis, or emphysema can be helped by palliative care. It is important to note that patients can receive palliative care while actively pursuing curative treatment for their conditions. In the early and middle stages of LBD palliative care can be handled by the individual's regular primary care physician and specialists. All LBD symptoms, such as constipation, sleep disorders, and behavioral problems, should be evaluated for their impact on the quality of life of the person with LBD and the primary family caregiver.

Palliative care has an especially important role in LBD because, by default, all current treatments focus on ameliorating symptoms rather than achieving a cure. And because of the multi-system nature of LBD, physicians from different specialties may be providing clinical care for the person with LBD; palliative care providers can coordinate the care provided by multiple physicians and help patients and caregivers express their feelings about which symptoms should be given priority. Another important aspect of palliative care is developing ongoing dialogue between the patient, family, and palliative care providers about whether interventions such as feeding tubes should be used as LBD progresses. Palliative care encourages early discussions about the creation of living wills and advanced healthcare directives.

Palliative care is available in a variety of settings including hospital-based programs as well as programs in skilled nursing and assisted living facilities. For patients who live at home, palliative medicine clinics also provide care on an out-patient basis. Palliative care providers work in concert with the primary care and specialist physicians who treat patients' LBD and any other conditions they have. The palliative medicine



specialist works with a team that typically includes nurses, social workers, physical therapists, dieticians, and pharmacists. The goals of this team are to provide:

- Relief from troubling symptoms
- Assistance in medical decision making
- Emotional and spiritual support
- Care coordination

Using a team-based approach incorporates multiple perspectives on patient care; facilitates communication amongst all health care providers; and creates an effective structure for problem solving. To find a palliative medicine specialist, ask a physician or local hospital for a referral or consult the American Board of Hospice and Palliative Medicine's website through the link provided in the Resources section at the end of this article.

Many types of health insurance cover the costs of palliative care. Although neither Medicare nor Medicaid recognize the term "palliative care," these programs do cover some palliative care medications and treatments as they do other medical care. The palliative care provider will bill Medicare Part B or Medicaid, but the patient or family may be responsible for co-payments or other fees. Ask the palliative care provider about these fees and ask for a fee schedule before beginning to receive care. Similarly, many private health insurers and managed care plans as well as long-term care plans provide some coverage for palliative care. Before beginning palliative care, ask the insurer about the extent of coverage provided.

### THE CLINICAL COURSE OF LEWY BODY DEMENTIA

The way in which LBD progresses varies from person to person. Some people experience a gradual worsening of LBD symptoms, while others experience periods of more rapid decline. Often LBD cognitive and behavioral symptoms worsen temporarily, because of pain, infection or other medical problem, but may improve once the problem is resolved. And while some LBD treatments may lessen certain symptoms for a period, there is no cure for LBD. The average duration of LBD (from the time of diagnosis to death) is 5 to 7 years.

The initial symptoms of LBD can vary by the individual, and may include visual hallucinations, acting out dreams or other sleep disturbances, cognitive impairment, or parkinsonian motor signs (these signs include tremor, rigidity, and problems with balance and movement). In general, the symptoms of LBD get worse as the disease progresses over a period of years, but there may be times when symptoms suddenly become much worse or mental abilities may fluctuate unpredictably. Medications that have anticholinergic or antipsychotic properties should be used cautiously, if at all, and may cause sudden and



sometimes severe deterioration. In the later stages of the disease, people with LBD are not able to do the basic self-care activities such as bathing, dressing, or toileting and often have increasing difficulties with movement that can affect walking, talking, and swallowing. These more severe problems also make it more difficult for the person with LBD to communicate or participate in activities and may cause weight loss, aspiration pneumonia, or falls that result in broken hips or wrists. When a person with LBD needs constant care to meet their basic needs (like feeding and toileting) and their quality of life is greatly reduced, it is an appropriate time to consider a hospice program.

## WHAT IS HOSPICE CARE?

A great deal of overlap exists in the ways in which palliative care and hospice care are organized and provided, as outlined in the table below. The primary difference is that hospice programs are intended for people who are in the later stages of an incurable illness that has progressed to the point where providing basic supportive care and measures to ensure comfort take precedence over treatments that attempt to slow disease progression. The goal of hospice care, like palliative care in general, is to offer relief from pain and other symptoms for the patients, while providing emotional support to patients and their families.

## COMPARISON OF THE FEATURES OF PALLIATIVE AND HOSPICE CARE

Feature	Palliative Care	Hospice Care
Goal	<ul style="list-style-type: none"> <li>• Pain relief and symptom control</li> <li>• Emotional support</li> </ul>	Same
Curative treatments	Curative treatments continue as long as individual desires	Curative treatments cease
Eligibility restrictions	None	Physician must certify that individual is unlikely to live more than 6 months
Team	<ul style="list-style-type: none"> <li>• Palliative care doctor</li> <li>• Primary care and specialist physicians</li> <li>• Nurses</li> <li>• Physical therapists</li> </ul>	Same as Palliative Care team plus: <ul style="list-style-type: none"> <li>• Home health aides</li> <li>• Chaplains</li> <li>• Volunteers</li> </ul>



Feature	Palliative Care	Hospice Care
	<ul style="list-style-type: none"> <li>• Dieticians</li> <li>• Social workers</li> <li>• Pharmacists</li> </ul>	
Interventions	Interventions to alleviate pain and symptoms	Interventions to alleviate pain and symptoms, may be more aggressive
Coverage	<ul style="list-style-type: none"> <li>• Medicare Part B</li> <li>• Medicaid</li> <li>• Most private health insurance</li> <li>• Patient/family responsible for co-payments, deductibles, or other fees</li> </ul>	<ul style="list-style-type: none"> <li>• Medicare Part A</li> <li>• Medicaid covers in 45 states</li> <li>• Most private health insurance</li> <li>• Patient/family responsible for small co-payments</li> </ul>

While there are no restrictions on who can receive palliative care, hospice care has some eligibility restrictions. The patient's doctor and the hospice's medical director must certify that the individual has a terminal illness and has six months or less to live if the illness is allowed to run its course. To receive Medicare's hospice benefit the patient also must be eligible for Medicare Part A, agree to choose hospice care instead of regular Medicare benefits to treat the terminal illness, and receive care from a Medicare-approved hospice program.

Like palliative care, hospice care teams consist of specially-trained nurses, physicians, social workers, physical therapists, dieticians, and pharmacists. However, the hospice team will also usually include chaplains and volunteers. In addition, a home health aide may come to assist with bathing, dressing, or feeding. Most hospice care is provided in the patient's home. However, there are hospice programs located in many assisted living and skilled nursing facilities as well as hospital-based and residential programs.

The interventions provided by the hospice team are similar to those previously described for palliative care, but they focus more on keeping the person comfortable in the later stages of their disease. For example, hospice nurses will teach family members how to provide comfort feeding for individuals who have difficulty swallowing, a common symptom in late-stage LBD. Also, hospice physicians may suggest periods of palliative sedation for individuals with LBD who suffer from severe hallucinations or delusions and are severely agitated and cannot sleep.



Hospice care is covered under the Medicare program. If an individual has Medicare Part A, then he or she is entitled to receive hospice services. The way in which hospice services are arranged and paid for under Medicare is more like a managed care plan than traditional fee-for-service Medicare. This can cause some confusion about what the Medicare hospice benefit will and will not cover. When a person elects to receive Medicare's hospice benefit and is admitted to a Medicare-approved hospice program, that program receives a fixed payment for each day of that person's care (a per diem). In return, the hospice program must provide all the care needed for that person's terminal illness. This includes:

- Physician services
- Nursing care
- Medical equipment (such as a hospital bed or wheelchair)
- Medical supplies
- Medication to control pain or other symptoms
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Dietary counseling
- Grief and loss counseling
- Short-term inpatient care (if pain or other symptoms cannot be controlled at home)
- Short-term respite care (up to 5 days at a time)

Out-of-pocket costs for hospice under Medicare are minimal. There is a \$5 copayment for each prescription medication and, if inpatient respite care is needed, there is a charge of 5 percent of the Medicare-approved cost of the stay. Medicare does not permit hospice programs to pay for some services including:

- Treatments to cure terminal illness
- Prescription medications to cure terminal illness
- Care from a hospice provider that was not arranged by the hospice care team
- Room and board in a nursing home, assisted living facility, or residential hospice



- Emergency room or inpatient hospital care or transportation in an ambulance unless these services have been arranged by the hospice team or are unrelated to the terminal illness

If individuals need care for other health problems that are not related to their terminal illness, then this care is not paid for out of the hospice payment but is covered by their regular Medicare benefit.

Individuals may continue to see their regular primary care physician and other health care providers for conditions unrelated to their terminal diagnosis (a podiatrist, for example).

Hospice care also is covered by most private insurance carriers, but check the plan's benefits to determine the extent of coverage available. As of December 2010, hospice care is covered by 45 of the 50 state Medicaid programs. Unfortunately, states are under tremendous pressure to control their Medicaid costs and several states have dropped hospice coverage from their Medicaid plans within the last year. Individuals should check with their state's Medicaid program to find out if it covers hospice services. If an individual decides that he or she no longer want hospice care or does not like a hospice program, that person may dis-enroll or switch to a different hospice program at any time for any reason without penalty.

### WHAT TO ASK WHEN CHOOSING HOSPICE

There are many hospice programs available – large and small, for-profit and not-for-profit, those with a religious affiliation and those without. Selecting an appropriate program will take some research. Here are some questions to ask:

- Is the hospice run as a for-profit or not-for-profit business?
- Does the hospice belong to the National Hospice and Palliative Care Organization?
- Does the hospice have experience with LBD patients?
- Does the hospice have experience dealing with patients who have severe delirium or hallucinations?
- Does the hospice have a full-time physician on staff that can be reached for emergencies at night and on weekends and holidays?
- Is the hospice “open- access” that is will the hospice provide all services and medications that a patient requires for pain control and symptom relief?
- Does the hospice have access to an inpatient hospital in the event that the patient's symptoms cannot be adequately handled at home?
- Will the hospice covered all the medications that your loved one is currently receiving (provide a list)? What about atypical antipsychotics (which can be quite expensive)?



- What types of bereavement services does the hospice provide (just written pamphlets or individual/group counseling as well)?

LBD places a tremendous burden on families. Palliative and hospice care helps individuals with LBD to maintain the highest possible quality of life and it provides families emotional support as they cope with their loved ones' progressively debilitating illness. Now widely available and affordable palliative and hospice care are much needed resources for individuals and families affected by LBD.

## ADDITIONAL RESOURCES AND READING

Artificial Nutrition and Hydration: Beneficial or Harmful? - by the American Hospice Foundation

American Academy of Hospice and Palliative Medicine – locate a palliative medicine physician in your state: <http://www.palliativedoctors.org>

HospiceDirectory.org- locate a hospice program by state or zip code: <http://www.hospicedirectory.org>

The Hospice Foundation's Hospice Information Center – lists tools for caregiver's tools a reading list: <http://www.hospicefoundation.org/>

Centers for Medicare and Medicaid Services – Describes Medicare's hospice benefits in detail: <http://www.medicare.gov/publications/pubs/pdf/02154.pdf>

Caring.com - useful resources about all aspects of caregiving including end-of-life care: <http://www.caring.com>

End of Life: Helping with Comfort and Care - by the [National Institute on Aging](#)





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**To learn more about LBD,  
visit [www.lbda.org](http://www.lbda.org)**

LBD Caregiver Link:

I-800-LEWYSOS

I-800-539-9767

[lbda@lbda.org](mailto:lbda@lbda.org)

By supporting the work of LBDA, you too will be

**Increasing Knowledge**

**Sharing Experience**

**Building Hope**

Lewy Body Dementia Association

404-935-6444

[www.lbda.org](http://www.lbda.org)

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