



# Care Partners' Role in Medications for Loved Ones with Dementia with Lewy Bodies

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*NOTE: This summary is based on a review of the professional and lay literature, a compilation of suggestions from reputable health resources, the author's personal experiences and observations, and ideas from care partners in a variety of online support groups. It is not intended to substitute for the reader's frequent interaction with a loved one's healthcare providers on the topic of medications used to treat the symptoms of dementia with Lewy bodies and other conditions.*

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Rosemary Dawson

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In Memory

Lilburn Dawson

1939 –2014

Released from the grip of DLB

## Acknowledgements

I offer my heartfelt thanks to the people who helped with this project. It began as a two-page project to summarize ideas for members of the LBD Caring Spouses online support group. Caring Spouses members have provided inspiration and contributed ideas. My hope is that current and future Caring Spouses and other DLB care partners benefit from this booklet.

My fellow Caring Spouses moderators, Pat Snyder and Jeff Maruna, supported me throughout the project, brainstormed ideas, and provided valuable feedback.

Helen Buell Whitworth, Sue Dawson, and Cheryl Austin gave me useful ideas to incorporate from their knowledgeable insights into DLB.

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Thanks to the two pharmacists who reviewed the booklet from a pharmacist's perspective. They are anonymous because of their pharmacy affiliations.

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Rosemary –Ro – Dawson

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## Important Note

**This booklet is not about the basics of dementia with Lewy bodies. There are many print and electronic resources that provide excellent information about the causes, risks, symptoms, diagnosis, and treatment of DLB. Some of these are listed in the Reference section starting on page 29. If you are not familiar with the basics of DLB, read one or more of the suggested resources.**

## Internet Links

**If you are reading this booklet online, click on the underlined blue text to go directly to the Internet site. If you are reading a print version, type the URL into your browser.**

# Introduction

One of the most commonly discussed topics in support groups for care partners of loved ones with dementia with Lewy bodies (DLB) is medications. Medications play an important role in the treatment of the symptoms of dementia with Lewy bodies, but there are no drugs that treat DLB itself. DLB is a multi-system disease, which makes treatment of its symptoms quite challenging. For example, medications used to treat one symptom (e.g., movement disorders/Parkinsonism) may cause negative reactions with respect to other symptoms (e.g., psychological and behavioral symptoms).

Many people with DLB are sensitive to and react negatively to both prescribed and over-the-counter (OTC) drugs—for example, OTC drugs containing diphenhydramine (e.g., Benadryl) and dimenhydrinate (e.g., Dramamine). At the far end of the continuum are antipsychotic drugs that can cause neuroleptic malignant syndrome (NMS), which can be fatal. Up to 50% of patients with DLB who are treated with *any* antipsychotic medication may experience symptoms of severe neuroleptic sensitivity, such as worsening cognition, heavy sedation, and/or increased and possibly irreversible Parkinsonism. The drugs used to treat the symptoms of DLB were developed to treat other diseases (e.g., Alzheimer's, Parkinson's, epilepsy, anxiety, sleep disorders, etc.). Studies indicate that some of these medications are effective with DLB symptoms. The challenge is compounded because people with DLB vary in how they react to different medications. For example, some people can take *atypical antipsychotics* (such as Seroquel) without significant negative side effects, while others have very severe adverse reactions.

Few DLB care partners have been trained as physicians or pharmacists, so what are they to do? The challenge is great because many healthcare professionals know too little about the medications used to treat the symptoms in people with DLB or about how drugs prescribed for other conditions might affect someone with DLB. Furthermore, most loved ones with DLB are unable to take an active role in assessing the relative merits and risks of potential medications.

Medications play an important role in the treatment of the symptoms of dementia with Lewy bodies, but there are no drugs that treat DLB itself.

# What Can DLB Care Partners Do?

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## Be proactive.

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Learn as much as you can about medications and DLB.

### Medications for Treating the Symptoms of DLB

Your first resource to download, save, and print is from the Lewy Body Dementia Association (LBDA) - the [Medications Glossary](http://lbda.org/sites/default/files/medication-glossary.pdf) (<http://lbda.org/sites/default/files/medication-glossary.pdf>).

This glossary was “developed for LBD families and provides helpful information about medications used to treat cognitive,



motor, mood, or behavioral disorders. The publication may be useful in discussing the risks and benefits of certain medications with healthcare providers.”

Other LBDA references to get you started are

- [LBD Treatment Options](http://www.lbda.org/content/treatment-options) ([www.lbda.org/content/treatment-options](http://www.lbda.org/content/treatment-options))
- [Treatment of Behavioral Symptoms: When to Consider Antipsychotic Medications in LBD](http://www.lbda.org/content/treatment-behavioral-symptoms-when-consider-antipsychotic-medications-LBD) (<http://www.lbda.org/content/treatment-behavioral-symptoms-when-consider-antipsychotic-medications-LBD>)

See also reliable resources from

- [Mayo Clinic](http://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/basics/treatment/con-20025038) (<http://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/basics/treatment/con-20025038>)
- [University of California, San Francisco](http://memory.ucsf.edu/education/diseases/dlb) (<http://memory.ucsf.edu/education/diseases/dlb>)
- [National Institute on Aging](http://www.nia.nih.gov/alzheimers/publication/lewy-body-dementia/treatment-and-management) (<http://www.nia.nih.gov/alzheimers/publication/lewy-body-dementia/treatment-and-management>).

## Potentially Dangerous Medications

“Some people with LBD are extremely sensitive, or may react negatively, to certain medications used to treat Alzheimer’s or Parkinson’s disease, as well as several over-the-counter medications. There are no definitive indicators as to whether a person with LBD will respond well or poorly to any particular medication. For that reason, treatment can be a delicate balancing act to improve certain LBD symptoms without worsening others.”<sup>1</sup>

Learn about the medications that can be dangerous for people with DLB. These include anticholinergics, benzodiazepines, antihistamines, antipsychotics, and others. (See the [Medications Glossary](http://lbda.org/sites/default/files/medication-glossary.pdf) (<http://lbda.org/sites/default/files/medication-glossary.pdf>).

Save and print the following resources:

[Beers Criteria \(Medication List\): Potentially Inappropriate Medications for the Elderly According to the Revised Beers Criteria \(2012\)](http://www.americangeriatrics.org/files/documents/beers/2012AGSBeersCriteriaCitations.pdf) (<http://www.americangeriatrics.org/files/documents/beers/2012AGSBeersCriteriaCitations.pdf>)

It is known that older adults are at an increased risk for adverse drug reactions because drugs are absorbed and distributed through their bodies differently, they often take many medications, and they have a variety of health conditions (comorbidities). Therefore, older adults, especially those with dementia, are susceptible to adverse effects from many medications.

[Anticholinergic Cognitive Burden \(ACB\) Scale](http://seniorshhealthknowledgenetwork.com/sites/seniorshhealthknowledgenetwork.ca/files/ACB_Anticholinergic_Burden_List_.pdf) ([http://seniorshhealthknowledgenetwork.com/sites/seniorshhealthknowledgenetwork.ca/files/ACB\\_Anticholinergic\\_Burden\\_List\\_.pdf](http://seniorshhealthknowledgenetwork.com/sites/seniorshhealthknowledgenetwork.ca/files/ACB_Anticholinergic_Burden_List_.pdf))

This scale identifies medications to avoid and also suggests safer alternatives. It includes medications that reduce the effect of acetylcholine in the brain and classifies them by the severity of their effects. Drugs in this class may worsen cognitive impairment, confusion, and hallucinations in individuals with DLB and should be avoided if possible according to the LBDA.

[List of benzodiazepines](https://en.wikipedia.org/wiki/List_of_benzodiazepines) ([https://en.wikipedia.org/wiki/List\\_of\\_benzodiazepines](https://en.wikipedia.org/wiki/List_of_benzodiazepines))

According to the LBDA, benzodiazepines may produce sedation and confusion in people with DLB and should be avoided. The adverse effects can lead to accidents and falls.

## Other Sources of Information

Excellent information about all drugs can be found on several reliable websites:

- <http://www.drugs.com/>
- <http://www.rxlist.com>
- <http://www.webmd.com/drugs/index-drugs.aspx>
- <http://www.nlm.nih.gov/medlineplus/druginformation.html> (Spanish version available)
- [www.mayoclinic.org/drugs-supplements](http://www.mayoclinic.org/drugs-supplements)

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# Keep good records.

## Share information with your loved one's healthcare team.

Provide all of your loved one's (LO) healthcare providers complete information about your LO's conditions, diagnoses, symptoms, and medications. They can take all of the information into account when prescribing medications to avoid adverse drug interactions and side effects common with DLB or another condition your LO may have. It is also important to coordinate medications across providers.

Your LO's medication list should include all drugs: prescription medications, OTC drugs, vitamins, supplements, and other herbal products.

Include all types of medications for internal and external use in various forms: pills, tablets, capsules, liquids, patches, creams, inhalers, injectable solutions, chewable or dissolving medications, suppositories, ointments, and drops.

See the next page for a sample medication management form. You can modify this to meet your needs. The form should include names of all medications. For each, record brand and generic names; illness or symptoms it treats; dosage (mg. units, puffs, drops); when to take it (times per day? a.m. or p.m.? with or away from meals?); why it is taken; when started and stopped; prescribed by; possible adverse reactions; and noted effects.

There are also applications for your computer, smartphone, and tablet that allow you to input medication and other health data for access at any time. One free application is [MyMedSchedule](https://secure.medactionplan.com/mymedschedule/index.htm) (<https://secure.medactionplan.com/mymedschedule/index.htm>)







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# Partner with a pharmacist.

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## Find a pharmacist knowledgeable about DLB.

Find a pharmacist who is knowledgeable about DLB, the medications for its symptoms, and the drugs that are potentially dangerous for people with DLB. Ask if a geriatric pharmacist is available. Talk with pharmacists and ask questions about DLB and medications to determine who has the level of knowledge needed to be a member of your LO's healthcare team. If English is not your first language and you need help understanding prescriptions, find a pharmacist who speaks your language.

If you can't find a DLB-savvy pharmacist in your area, find one who is willing to learn. Provide the pharmacist with the references listed at the end of this booklet.

Fill all of your LO's prescriptions at the same pharmacy with the same DLB-knowledgeable pharmacist. That one person will be aware of all the medications your LO takes and can watch out for potential drug interactions and drugs that should be avoided.

Investigate special programs that can assist you with prescriptions, refills, tracking, compliance, and other medication delivery issues.



- [Simplify My Meds](http://www.lbda.org/content/simplify-your-medicines): The National Community Pharmacists Association has a program that provides pharmacists with the tools to help coordinate patients' prescription refills to a single day of the month. This is available only at independent community pharmacy members (<http://www.lbda.org/content/simplify-your-medicines>).
- Online pharmacy programs with major pharmacies (Walgreen's, CVS, Rite Aid, etc.) that allow you to keep track of all of your LO's medications, request refills, check for drug interactions, etc.
- Pharmacy applications for your computer, smartphone, and tablet.
- Programs that deliver medications to your home – mail order or home delivery from your pharmacy.

If your LO has several physicians prescribing medications independently of one another and no doctor is monitoring the total load of medications, ask a knowledgeable pharmacist to review all of your LO's medications with the goal of identifying any drugs that interact with each other (increasing, decreasing, or otherwise affecting their outcomes).

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# Collaborate with the DLB doctor.

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Your loved one's doctor is the key to effective medication.



If your LO has several physicians prescribing medications, ask one – probably the doctor managing the DLB symptoms or the primary care physician – to monitor the total load of medications.

Keep all of the doctors fully informed about your LO's conditions, diagnoses, symptoms, and medications. If there are several to many doctors, each should be aware of what the others are doing, especially with respect to medications.

Encourage your LO's doctors to avoid adverse reactions to medications by

- introducing medications one at a time
- starting new medications at the lowest dose possible
- increasing dosages slowly while carefully monitoring for positive and negative reactions
- terminating the medication if there are negative reactions or when the drug is no longer needed.

Ask your LO's doctor to review your LO's medications at least once a year. The need for a medication can change as an illness improves or gets worse or as a person loses or gains weight. Remember that older people may need a smaller dose because drugs stay in their systems longer.

If your LO has been taking some medications for a long time, ask the doctor if each medication is still needed, if it is still effective, if there is a less expensive generic to replace a brand name, and if there is a newer medication that would be more effective.

When your LO's doctor prescribes a medication, be sure to get answers to the Questions about Prescriptions (see the following pages).

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# Questions about Prescriptions

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## Obtain this information about each of your LO's prescriptions.

Some of this information can come from your LO's doctor, some from the pharmacist, some from the prescription label, and some from the written material that comes with the medication. There are also excellent sources of information about drugs on the Internet (see the references starting on page 29).

### A. Basic identifying information

1. What is the name of the medication? Be sure to get the correct spelling, as some medications sound alike but are quite different.
2. What does this drug look like (size, shape, color)? You want to be sure that the pharmacist gives you the correct medication.
3. Is this a brand name or generic drug?
4. If it is a brand name medication, is a less expensive generic available?

### B. Questions for your loved one's doctor

1. Why are you prescribing this drug? What is the purpose of the medication?
2. Are there other drugs to treat this symptom/condition? If so, why are you prescribing this drug instead of one of the others?
3. If a generic is available, why have you prescribed the brand name? Is the generic as effective as the brand name?
4. What results should I look for in my LO with this drug?
5. How long will it take to observe the effects of the medication?
6. How long will it take to know if the medication is not working for my LO?
7. Have you prescribed this drug for other patients with dementia with Lewy bodies? If so, how effective has it been?
8. What are the primary short-term adverse side effects of this medication – especially for someone with DLB? What should I look for in my LO?
9. What are the potential long-term adverse side effects – especially for someone with DLB? What should I look for in my LO?
10. Are there ways to minimize the short- or long-term adverse side effects?
11. If my LO shows adverse side effects, what should I do?

### C. Information about when and how to take the medication

Although you will receive written instructions, ask the doctor or the pharmacist if the answers to any of the following are not clear.

1. How many times a day should it be taken?
2. When should it be taken?
3. What is the correct dosage?
4. Should it be taken with food or on an empty stomach?
5. Can it be taken with beverages other than water?
6. Can it be crushed if it is a tablet or pill?
7. Can the contents be emptied if it is in a capsule?
8. What should we do if we miss a dose?
9. If it is a patch, where should the patch be placed? How often and when should it be changed?
10. If it is an injection, where is the injection site?

### D. Other important information

1. How and where should the medication be stored?
2. Can the medication interact with any of the other medications my LO is currently taking (both prescription and over-the-counter)? If so, what needs to be modified?
3. Are there foods (e.g., grapefruit), beverages (e.g., alcohol), drugs (e.g., OTC meds, vitamins, or herbal supplements), or activities (e.g., being in sunlight) my LO should avoid while taking this medication?
4. If my LO can't take the medication in its prescribed form (e.g., a large pill that can't be crushed or a capsule that can't be emptied), is it available in another form (e.g., liquid)?





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# Be aware of polypharmacy.

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## Multiple medications can pose risks to your loved one.

**Polypharmacy** – when a person is taking too many medications. This is a common problem among people who are being treated for several to many conditions. It can result in dangerous drug interactions and multiple adverse drug effects. Contributing to polypharmacy are prescription medications, over-the-counter medications, and supplements.

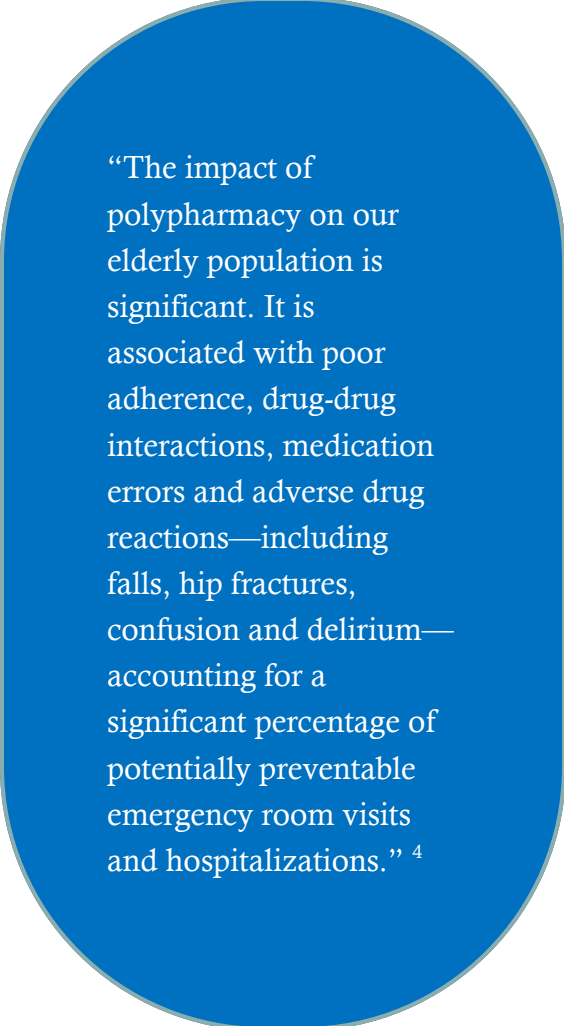
The risk of adverse reactions and drug interactions increases with the number of medications a person takes. The drug categories most commonly involved in adverse reactions are cardiovascular agents, antibiotics, diuretics, anticoagulants, hypoglycemics, steroids, opioids, anticholinergics, benzodiazepines, and nonsteroidal anti-inflammatory drugs (NSAIDs).<sup>2</sup>

The elderly, even those without any type of dementia, are likely to suffer the effects of polypharmacy. 90% of people 65 and older take at least one drug per week, more than 40% take five or more different drugs per week, and 12% take ten or more drugs per week.<sup>3</sup>

Often, a medication is prescribed to treat the side effects of another medication. Sometimes, that medication has side effects, too; yet another drug is prescribed to try to manage those side effects. This is called the *prescribing cascade*.

Ask your LO's doctor to perform a drug regimen review at least annually and when prescribing new medications. Ask the following questions:

- Can any of the current drugs be removed? Ask that they be deprescribed.
- Are there any negative interactions between the medications my LO is taking?
- Can any of the symptoms or conditions my LO is having be due to one or more of the medications?



“The impact of polypharmacy on our elderly population is significant. It is associated with poor adherence, drug-drug interactions, medication errors and adverse drug reactions—including falls, hip fractures, confusion and delirium—accounting for a significant percentage of potentially preventable emergency room visits and hospitalizations.”<sup>4</sup>

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# Manage the medications.

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## Be prepared to administer your LO's medications.

Always read the patient information sheet that comes with each prescription and other medication (OTC, vitamins, supplements, etc.). This can be frustrating, however, because the content, format, reading level, and excessive length of some of these materials make them difficult to understand. That is why discussions with your LO's DLB doctor and pharmacist are so important.

Check the prescription label for special warnings or advice.

Be certain that your LO takes medications as prescribed: the correct dosages, at the correct times, with or without food, etc. Know what medications can be crushed or removed from their capsules and those which must not be.

If your LO takes several medications, get an organizer and sort them for the week or longer. Consider other types of storage containers such as automatic pill boxes that can be set to open at specific times.



Ask your pharmacy if they prepare bubble packs with the correct dosages in each pack.

Keep the bottled and sorted medications out of your LO's reach. Store as directed (e.g., refrigerated; in a cool, dry location). Be sure that no one else takes your LO's medications. If there are children in the home, keep all medications out of their reach.

Do not run out of medications; order refills in sufficient time for them to be filled. Some medication programs manage refills so that you won't run out.

Safely dispose of any medications that are past their expiration or "use by" date.

Monitor your LO's reactions to new medications. Note any changes – positive and negative – in behavior, sleep, cognition, movement, autonomic functions (urinary and bowel activity, blood pressure, temperature regulation, etc.), appetite, communication, and whatever else you observe. Record your observations and share them with the prescribing physician.

# Administer your LO's medications.

## Learn what you can do to make this activity go smoothly.

Decreases and fluctuations in your loved one's cognition because of DLB are reasons for you to administer medications and not leave this task to your LO.

### *Have on hand*

- Medication dosage organizer
- Medicine cups (disposable or reusable)
- Liquid in appropriate container
- Soft food (yogurt, pudding, applesauce, etc.)
- Pill splitter
- Pill crusher

Have a schedule based on when your loved one needs to take each medication. Try to limit the number of times a day you dispense medications. Ask the doctor to help you coordinate the schedule if your LO takes several or more medications. Aim for no more than two to three times a day; perhaps morning (before or after breakfast) and evening (before or after dinner or before bedtime) OR before or after each meal. This will depend on whether the drug should be taken with food. Aim for a time when your LO is not fatigued.

Consider the environment. Find a place that is quiet and free from distractions. This will keep your LO calm and allow you to focus on the task to avoid making mistakes. Select one or two places so that your LO feels comfortable and gets used to taking medications there.

Wash your hands before touching any medications or items that you use to give them to your LO.

To prevent choking, regurgitation, or aspiration, be sure that your LO is in a sitting or semi-sitting position. If in bed, raise your LO's upper body with pillows or adjust the hospital bed.

Have the medications ready; preferably, the pills and capsules should be in a dosage organizer.

Also have liquid close at hand to help your LO swallow the medications. Many medications need to be taken with a full glass of water or other liquid. Determine what liquid works best for your LO: water, juice, milk, smoothie, coconut water, etc. Verify with the doctor or pharmacist that the liquid is appropriate.



Use the kind of liquid container that works best for your LO so that she swallows the pills without coughing, choking, or aspirating: a normal glass or cup, a “sippy” type cup, or a glass with a straw.



Place one pill/capsule (perhaps two if they are small) in a medication cup. This can be a disposable paper cup or a reusable cup of a similar size. If your LO has many pills to take, don't give them all at once.

If your LO has sufficient eye-hand coordination and can follow directions, you can hand the medication cup to him with the directions to swallow the pills. Often, however, a person with DLB will be unable to do this. Instead, give simple verbal instructions, place the cup against the lower lip which will cue him to open his mouth. If he doesn't open his mouth, give further verbal directions and/or stroke his cheek. Tip the meds into your LO's mouth. Do not use your hand to get the medications into his mouth. It is always good to use physical and verbal cues. Use simple language and clear instructions.

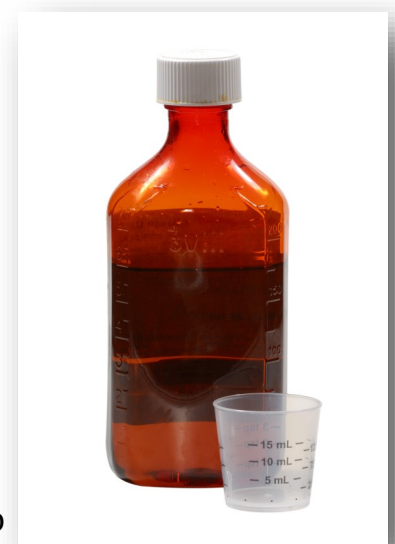
Offer the water or other liquid to your LO if she can handle getting the container to her mouth. If not, place the container against her lips, encourage her to open her mouth, and cue her to swallow. Try to get the liquid into her mouth as soon as possible so that she swallows the pills quickly before they dissolve or start to taste bad in her mouth and before she can try to spit them out.

Stay with your LO to make sure that he swallows the medication. Some people with DLB hold the pills in their mouths and then spit them out when no one is looking – or even when someone is looking.

If your LO takes a liquid medication, give it with the measuring cup or spoon that came with the medication. Do not use a household spoon, for example. You want to be sure to give the correct dosage.

Do not rush your loved one. As with most tasks, being patient and calm helps both of you. Your pleasant demeanor, a smile, and soothing words will reassure your LO.

Have emergency numbers and the number of your local poison control center handy. If you think that your LO has a problem due to medication or suspect a medication overdose, call one of these emergency numbers.



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# Be ready for problems administering medications.

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Sometimes people with DLB have difficulty taking medications or resist doing so.

Expect to have times when your loved one won't be able to or will not want to take medications. This may be for physical reasons or for emotional/psychological reasons.

## Dealing with Physical Reasons

A very common physical reason for people with DLB not being able to take their medications is their inability to swallow the pills, tablets, or capsules. When this happens, you have several options, but *you must obtain advice from your loved one's doctor or pharmacist.*

Some pills and tablets are very large – too large for your LO to swallow whole. If they are scored, use a pill splicer to cut them in half and give your LO half at a time. If they are not scored, ask the doctor or pharmacist if you can cut them in half.

No pill/tablet should be crushed or capsule emptied without first consulting your loved one's physician or pharmacist!

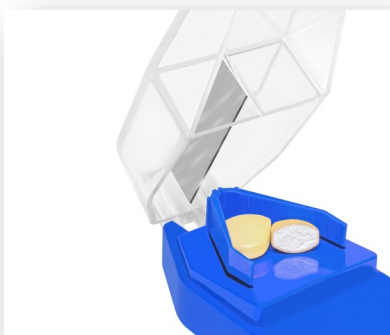
Some medications can be crushed, but doing so with other tablets can affect their effectiveness or cause harm. For example, crushing an extended release tablet would deliver too much into the system at one time rather than at regular intervals throughout the day. Also, do not crush enteric-coated tablets. The enteric coating delays the release of drugs that can irritate the stomach or be degraded by stomach acid.

For a list of drugs that should not be crushed, see [Oral Dosage Forms That Should Not Be Crushed](http://www.ismp.org/Tools/DoNotCrush.pdf) (<http://www.ismp.org/Tools/DoNotCrush.pdf>).



If you confirm that some or all of your loved one's pills/tablets can be crushed, use a pill crusher or a mortar and pestle to crush them into a fine powder. Sprinkle the crushed medication into a favorite, easy-to-swallow food such as yogurt, pudding, or applesauce that has also been approved by the doctor or pharmacist. Mix a small amount of the medication with a small amount of the food and continue with spoonfuls to be sure that your LO gets the full dosage. If you mix all of the crushed medication into a full container of yogurt, for example, your LO might not eat all of the yogurt and you won't know how much of the medication has been consumed.

Similarly, determine which, if any, of the capsules your LO takes can be emptied and added to food.



If you cut or crush a pill, clean the pill cutter or crusher before and after its use.

If a pill cannot be crushed or a capsule emptied, seek advice from your LO's doctor or pharmacist about placing the intact pill or capsule in a mouthful of food (yogurt, pudding, applesauce, etc.).

Ask about using an over-the-counter pill swallowing spray that creates a water-based barrier between the tablet and the tongue and throat, thereby preventing the "stuck in the throat" feeling.

Try gently rubbing your LO's throat to stimulate swallowing. As people with DLB lose the ability to swallow, care partners need to try many things to help them with their medications.

Many people with LBD use an Exelon (rivastigmine) patch. Follow the directions carefully! Replace the patch every 24 hours, being sure to remove the old patch. Change the position of the patch daily to avoid skin irritation, and do not apply to skin that is wet or oily, red or sore. The patch is usually applied to the back because your LO is less likely to remove it.

Some of your LO's medications may be available in a form that is easier to take than a pill or capsule: a liquid; a dispersible (disintegrates in water); a buccal (dissolves when held between cheek and gum); a sublingual (dissolves under the tongue); a patch; a suppository; a cream; or an inhaled version. Ask your LO's doctor or pharmacist or check for alternatives on line at [Check My Medicine](http://www.swallowingdifficulties.com/check-my-medicine) (<http://www.swallowingdifficulties.com/check-my-medicine>).



If an alternate form is not available, you may need to see if a *compounding pharmacy* can help. These pharmacists can combine several medications to simplify administering them; prepare medications in a form that your LO can take more easily; and/or add flavors to make them taste better.

People who have problems swallowing medications, foods, and/or liquids have a condition known as *dysphagia*. Ask for a referral for an assessment by a speech and language therapist to determine the extent of your LO's difficulty and for suggestions for the most appropriate forms of medication and ways to take them.

Ask the doctor to review all of the medications your loved one takes to see if any that are causing problems because of dysphagia can be discontinued.

### **Dealing with Emotional/Psychological Reasons**

It is not uncommon for a person with DLB to resist taking medications, at times withdrawing to avoid taking them and at other times becoming aggressive verbally and physically toward the person trying to administer the medications. When this happens with your LO, remember that it is the disease that is causing the behavior; your LO is not intentionally acting in this way. Do not take it personally.

Your LO with DLB has diminished and fluctuating cognition that interferes with the ability to receive, process, and respond to stimuli such as your requests to take medications. The progressive cognitive and functional deterioration plus a host of stressors lead to dysfunctional behaviors such as resisting taking medications, sometimes in hostile or violent ways.

First, consider the stressors that might bring on the negative behavior:

- being overly tired—fatigued
- experiencing changes in routine, surroundings, or people
- being asked to do something beyond his functional ability
- being bombarded with too many stimuli competing for attention
- responding to feelings of loss with anger or aggression
- being stressed physically with pain, discomfort, immobility, etc.



Determine what you can do to reduce or eliminate these stressors. The suggestions in the previous sections address many of these stressors.

People with DLB may also experience paranoid delusions. Perhaps your loved one thinks that you are trying to poison him or hurt him in some way with the medications. This is his reality, so trying to reason with him will be futile.

Do not argue or cajole. You will both become frustrated, and it won't change your LO's behavior; in fact, it is likely to make the situation worse and spread to other areas of your interactions.

So, what can you do when faced with these behaviors? Some of the strategies outlined in the previous section may work: crush the pills and disguise the medication in foods your loved one likes or obtain the medication in a different form that your LO may resist less.

Sometimes, it is enough to walk away and go back when you both are calmer. When your LO has calmed down, act normally. Your LO may accept the medications willingly. Just waiting awhile and coming back with a new approach can reset your LO's behavior.

If there is another person available, your LO might accept the medication from him/her.

If you anticipate resistance, give your LO the medications that are more important first to have a better chance of getting them down. Often any time-release pills that cannot be crushed should be done first.

You may be able to distract and offer rewards. For example, intersperse the medications with a food that your LO enjoys. Offer your loved one a small snack she likes - a piece of cookie or a bite of ice cream - with one pill. When she's finished that, offer another treat followed by another pill.

Ask your LO's doctor if one or more medications can be discontinued. Having fewer medications can lessen the aggravation for both of you.

Sometimes, you just may not be able to get your LO to take the medication. Know ahead of time what to do when your LO misses a dose of each medication. The doctor or pharmacist can tell you this, or the information will be in the consumer advisory sheet that comes with each prescription. The advice may be to skip the missed dose and resume the usual dosing schedule and not double the dose to catch up. This will vary from one medication to another, so be sure to check for each medication. Make a notation of any missed doses.

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# Two variations

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**Here is what you can do when your LO can still perform some medication-related tasks and when your loved one is not living at home.**

## **When Your Loved One Can Still Perform Some Medication-related Tasks**

If your LO has been diagnosed with DLB, one or more of the symptoms will prevent her from managing and taking medications and you, as the care partner, will have to take over these responsibilities. Early on, perhaps before diagnosis, symptoms can be mild, and people with DLB can function with moderate, occasional difficulty. As DLB progresses, however, your loved one will need more and more help with many tasks, including taking medications. Your LO may be reluctant to accept help, see it as a loss of independence, and not want to admit that she can't learn something or do things that she was able to do in the past.

Here are some things you can do.

1. Make notes of which symptoms of DLB your spouse has that interfere with her ability to be responsible for medications.

- Diminished cognition in the areas of problem solving, reasoning, decision making, following instructions, performing sequential tasks
- Unpredictable changes in concentration, attention, and alertness
- Visual-spatial problems
- Parkinsonism: loss of coordination, small tremors
- Memory problems
- Behavioral and mood changes

2. Ask your LO's DLB doctor to assess her ability to perform the tasks associated with medications. Of course, there always is the possibility that [show time](http://lewybodydementia.blogspot.com/2012/05/fluctuating-cognition-blessing-and-bane.html) (lewybodydementia.blogspot.com/2012/05/fluctuating-cognition-blessing-and-bane.html) will boost her performance. Have the doctor explain why it is important for you to take over some - or all - of the medication tasks. Often people with DLB will accept changes from their doctor more readily than they do from their care partner.

3. If your LO now has some or all responsibility for her medications, monitor how well she is doing. Have the medications in a sorter that you can check to verify that she has taken the medications. You will have to observe her directly to see if she is taking them on time, in the correct way, with the appropriate liquid, etc. Make a note of what she is not doing correctly. You will need to do this more than once because what she does right one day, she could do wrong the next due to the DLB fluctuations.
4. Provide tools to assist your LO in remembering to take medications. These must be tools that she can use. For example, a computer application will not be helpful if your LO no longer remembers how to use a computer. The same applies for a smartphone, tablet, or other electronic device that might alert your LO that it is time to take medications.
5. Store medications in a way that allows your LO to take them in the correct dosage at the correct time. *You* should sort the medications to be sure that the right pills and capsules are in the correct compartment of a simple sorter that has a removable compartment for each day of the week. This may be sufficient *early on*. The risk is that your LO will take pills and capsules from the wrong section, take medications from more than one section, or drop and spill the medications from the container.
6. If the current system is not working and you and your LO still want her to continue to be responsible for taking her medications, invest in one of the automatic pill dispensers and reminders that have the following features. Do a search online to find many such devices that vary in features and cost. Look for an organizer that

- organizes medications by day and time
- has room for all of your LO's medications
- has an alarm that requires the user to interact with the device to silence the alarm
- has an alarm that can be heard throughout the home but won't scare your LO
- dispenses the medications for only the right day and time
- locks
- cannot be tampered with by your LO
- possibly has a remote device via cell phone or computer that allows you to monitor if the medications have been taken.



Eventually, perhaps sooner than you now expect, you or someone else with good judgment and adult reasoning will have to take over **all** aspects of your LO's medications, following the guidelines in the previous section on administering medications.



## When Your Loved One is not Living at Home

If your loved one is in an assisted living facility or nursing home, a staff member – usually a nurse – will administer medications. You still have a role in this aspect of your LO's care. Here are some things that you can do.



1. Determine how knowledgeable the staff members are about DLB, the symptoms, and cautions about medications. If they are not knowledgeable, provide references in print or online to help them learn about DLB and medications. See the list of resources at the end of this booklet.
2. Provide the staff with information about what has worked and has not worked when you or another person gave your LO medications at home.
3. Be sure that they have your LO's complete medication history and up-to-date list of medications and allergies.
4. Observe the staff when they administer medications to your LO. Do they follow the guidelines outlined in this booklet? If not, discuss any differences. Request that they follow safe protocols.
5. Prior to an incident of your LO resisting medication, find out how they handle resistance and aggressive behavior. Provide the information from this booklet about how to handle resistance.
6. Ask how they ensure that your LO is given the correct medications at the right times.
7. People with DLB do best with routine and continuity of care. Encourage staff to have as few people as possible administer your LO's medications at the same times in the same way every day.
8. Monitor the staff's interactions with your LO when they administer medications. How the person approaches your LO—the attitude and demeanor—affects how your LO will respond. Note the non-verbal as well as the verbal behavior. If the person is patient, calm, gentle, relaxed, and not rushed, your LO is likely to respond positively.
9. If you are not satisfied with any aspect of how your LO is being given medication, talk with the director of the facility or its patient representative.

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# Explore non-pharmacological approaches.

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## Not all DLB symptoms require medication.

Remember that not all DLB symptoms require medication. Try non-pharmacological approaches, especially if your LO is sensitive to drugs and has adverse reactions. These approaches have been found to be successful in treating the behavioral and psychological symptoms of DLB either alone or in combination with drug therapies. According to a recent study, “The evidence for non-pharmaceutical approaches to the behavior problems often seen in dementia is better than the evidence for antipsychotics, and far better than for other classes of medication.”<sup>5</sup>

**Massage therapy.** Massage therapy can take several forms. The care partner or another caregiver can use therapeutic touch on a regular basis to promote relaxation and sleep, reduce anxiety and agitation, and lessen rigidity. A professional massage therapist might treat a person with DLB in a variety of settings. Massage therapy is often used with aromatherapy.

See

- <http://www.lbdtools.com/massage.html>
- <http://www.khca.org/files/2014/10/Therapeutic-touch-and-accupressure.pdf>

**Aromatherapy and essential oils.** Pure essential oils can be used in several ways. They can be diffused throughout the room or sprayed on bed linens. They can also be diluted with a pure carrier oil, such as olive or coconut oil, for use in massage therapy. Many care partners find that lavender works very well in calming and relaxing a person with DLB.

See

- [http://www.lbdtools.com/essential\\_oils.html](http://www.lbdtools.com/essential_oils.html)



**Music therapy.** As with other non-pharmacological approaches, music therapy can be implemented by a professional therapist. Some residential facilities provide this type of treatment. Care partners can also use music to address different symptoms. Calming and relaxing music can reduce agitation and promote sleep. Up-tempo music can stimulate the brain and increase awareness. Familiar music can awaken memories and encourage conversation. Music can arouse a desire to move in a person with DLB.

See

- <http://lewybodydementia.blogspot.com/2013/05/the-value-of-music-with-dementia.html>
- <http://www.todaysgeriatricmedicine.com/news/story1.shtml>

**Pet therapy.** Pets, especially dogs, can improve the physical and mental health of people with dementia. Many facilities for older adults, such as memory and dementia centers, have therapy animals. Household pets offer people with dementia companionship and affection.

See

- <http://www.khca.org/files/2014/10/Animal-Therapy.pdf>
- <http://alzheimersproject.org/About-Us/News-Photos-and-Calendar/Latest-News/Pets-and-Dementia>

**Art therapy.** Art therapy can engage people with dementia in activities that give them pleasure and that also limit their negative behavioral symptoms. Art therapists and other facilitators work in facilities for the elderly. Care partners can engage their loved ones in art activities at home.

See

- [http://www.lbdtools.com/art\\_therapy.html](http://www.lbdtools.com/art_therapy.html)
- [http://ccn.upenn.edu/chatterjee/anjan\\_pdfs/Chancellor\\_ArtTherapy\\_AD\\_JAD.pdf](http://ccn.upenn.edu/chatterjee/anjan_pdfs/Chancellor_ArtTherapy_AD_JAD.pdf)

**Other non-pharmacological approaches.** Trained therapists do the following:

- Physical therapy often provides cardiovascular, strengthening, flexibility, and gait training. General physical fitness training also benefits people with DLB (aerobic, weight, dance, water, and other activities).
- Occupational therapy helps people with their activities of daily living (ADLs).
- Speech therapy helps not just with speech, but also with swallowing and cognition.

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# Be prepared for ERs and hospitals.

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## Standard protocols in ERs and hospitals can pose risks to your LO.

Emergency room and other hospital personnel often do not have much, if any, background in DLB. Be prepared to share the following when there is the need for a trip to the emergency room or hospital:

### [The LBD Medical Alert Card](http://lbda.org/sites/default/files/lbda-wallet-card.pdf)

(<http://lbda.org/sites/default/files/lbda-wallet-card.pdf>)

### [Emergency Room Treatment of Psychosis factsheet](http://lbda.org/sites/default/files/emergency_room_treatment_of_psychosis.pdf)

([http://lbda.org/sites/default/files/emergency\\_room\\_treatment\\_of\\_psychosis.pdf](http://lbda.org/sites/default/files/emergency_room_treatment_of_psychosis.pdf)).

**Lewy Body Dementia Association, Inc.**  
www.lbda.org  
Caregiver Helpline  
1-800-LEWYSOS  
1-800-539-9767

Thank you to the **LBD Scientific Advisory Council** for their medical review in the creation of this card.  
This card made possible by  
Novartis Pharmaceuticals. ©2008

The information on this card is intended for general informational use only. It is not intended to be medical advice or to take the place of competent medical professionals who are familiar with a particular patient's situation. Each individual is advised to make an independent judgement regarding the content and the use of this information.

**MEDICAL ALERT CARD**

I have a disorder of the brain known as **LEWY BODY DEMENTIA (LBD)** which could make me appear confused and have difficulty moving or speaking normally.

**Please call my family or my physician!**

My Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Person to Call: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Physician: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Allergies: \_\_\_\_\_  
Other Medical Conditions: \_\_\_\_\_

## Your Role in Medication Reconciliation

Did you know that the average patient is at risk of at least one medication error per day while hospitalized?<sup>6</sup> Studies indicate that medication errors are among the most common patient safety error.<sup>7</sup> These errors often happen when a patient is handed off during admission, transfer, and discharge. During these transitions in care, patients often receive new medications or have changes made to their existing medications. What can you do as a care partner to avoid such errors when your loved one is hospitalized?

Find out how the hospital uses *medication reconciliation*, a formal process that creates a complete and accurate list of a patient's current medications and compares it to those in the patient record or medication orders during each transition. This practice reduces the risk that your LO will get incorrect medications, or medicines at the wrong doses. The goal is to minimize the potential for adverse drug effects and hospital readmissions by avoiding errors of omission, duplication, incorrect doses or timing, and adverse drug-drug or drug-disease interactions.

The medication reconciliation process hinges to a large extent on the information you provide about your loved one's medications – another reason for you to keep a comprehensive record of all your LO's medications.

## When your loved one needs anesthesia or sedation

If your LO needs a surgical procedure, meet with the anesthesiologist to discuss the sensitivities and risks posed by DLB. It is not unusual for people with DLB to react to certain anesthetics and surgery with acute states of confusion or delirium. They may experience a precipitous decrease in functional abilities which may not be reversible. Explore alternatives to general anesthesia, such as a spinal or regional block, that are less likely to result in postoperative adverse reactions.

“Cholinergic brain cells that produce acetylcholine regulate higher cognitive functions such as attention, memory and learning new skills. Most types of general anesthetic agents reduce the release of acetylcholine and may depress the cholinergic system in the central nervous system. This causes impaired consciousness and inattention, as well as changes in movement. Research has shown that the cholinergic system is already mildly impaired in the elderly people because of the age related changes. When anesthesia is used for surgery, it further impacts these neurons in normal elderly people. The effect is more pronounced in elderly LBD patients because of their marked baseline cholinergic losses.”<sup>8</sup>

Remember that sedation is used not only for inpatient and outpatient surgery, but also for many outpatient procedures such as colonoscopies and cardiac catheterizations, as well as procedures in dental and eye care offices. In each case, discuss the medications that will be used and ask the doctor to use those least likely to cause problems for your LO with DLB.

In addition to avoiding anticholinergics, ask the doctor and anesthesiologist about alternatives to benzodiazepines such as Versed (midazolam). Older adults are very sensitive to this drug, which increases the risk of its adverse effects. It also takes more time for older adults to recover after Versed is used. With DLB, these risks increase. Especially when a small amount of sedative is needed, a good alternative is Propofol (diprivan), a sedative that can also pose risks, but in many cases fewer than with Versed.

People with DLB can react very badly to some anti-nausea treatments, so if your LO needs an anti-nausea medication after surgery, ask about Zofran (onadansetron), which has fewer adverse effects.

Your role is to be sure that the doctor and anesthesiologist are aware that your LO has DLB. They need to know about the drug sensitivities of people with DLB and the potential for adverse drug effects, and alternatives to potentially dangerous anesthesia, taking into account the risks and benefits of each alternative.



# References

**For you, your LO's doctors, pharmacist, and hospital and ER staff**

## **Resources to Learn More about DLB**

*A Caregiver's Guide to Lewy Body Dementia* (October, 2010)

Book by Helen Buell Whitworth and James Whitworth

*Managing Cognitive Issues: in Parkinson's & Lewy Body Dementia* (May 2, 2015)

Book by Helen Buell Whitworth and James A Whitworth

[Lewy Body Dementia: Information for Patients, Families, and Professionals](#)

A 44-page booklet from the National Institutes of Health NIH Publication No, 13-7907  
September 2013

Download at [http://www.lbda.org/sites/default/files/lewybodydementia-final\\_11-6-13.pdf](http://www.lbda.org/sites/default/files/lewybodydementia-final_11-6-13.pdf) or <http://www.nia.nih.gov/alzheimers/publication/lewy-body-dementia/treatment-and-management>

Lewy body dementia

Website of the [Mayo Clinic](#)

<http://www.mayoclinic.org/diseases-conditions/lewy-body-dementia/basics/treatment/con-20025038>

Lewy Body Dementias

Website of the [University of California, San Francisco](#) at <http://memory.ucsf.edu/education/diseases/dlb>

## Resources to Learn More about Medications and DLB

### [Medication Glossary: Drug Classes and Medications \(2014\)](#)

A 15-page booklet from the Lewy Body Dementia Association (LBDA)

Download at <http://www.lbda.org/sites/default/files/medication-glossary.pdf>

### [Medical Alert Card \(2008\)](#)

Wallet card for people with DLB from the LBDA

Download at <http://www.lbda.org/sites/default/files/lbda-wallet-card.pdf>

### [Emergency Room Treatment of Psychosis factsheet](#)

A 5-page factsheet for emergency room physicians and other personnel

Download at [http://lbda.org/sites/default/files/emergency\\_room\\_treatment\\_of\\_psychosis.pdf](http://lbda.org/sites/default/files/emergency_room_treatment_of_psychosis.pdf)

### [Treatment of Behavioral Symptoms: When to Consider Antipsychotic Medications in LBD](#)

A 9-page brochure from the LBDA

Download at [http://www.lbda.org/sites/default/files/treatment\\_of\\_behavioral\\_symptoms.pdf](http://www.lbda.org/sites/default/files/treatment_of_behavioral_symptoms.pdf)

### [LBD Treatment Options](#)

LBDA Website

[www.lbda.org/content/treatment-options](http://www.lbda.org/content/treatment-options)

Excellent information about all drugs can be found on several reliable websites:

- <http://www.drugs.com/>
- <http://www.rxlist.com>
- <http://www.webmd.com/drugs/index-drugs.aspx>
- <http://www.nlm.nih.gov/medlineplus/druginformation.html> (Spanish version available)
- [www.mayoclinic.org/drugs-supplements](http://www.mayoclinic.org/drugs-supplements)

## Resources to Learn More about Drugs to Avoid or Use with Caution

### [Beers Criteria \(Medication List\): Potentially Inappropriate Medications for the Elderly According to the Revised Beers Criteria \(2012\)](#)

A 14-page brochure from the American Geriatrics Society

Download at <http://www.americangeriatrics.org/files/documents/beers/2012AGSBeersCriteriaCitations.pdf>

### [Anticholinergic Cognitive Burden \(ACB\) Scale](#)

A 1-page chart from the IU Center for Aging Research

Download at [http://seniorshhealthknowledgenetwork.com/sites/seniorshhealthknowledgenetwork.ca/files/ACB\\_Anticholinergic\\_Burden\\_List\\_.pdf](http://seniorshhealthknowledgenetwork.com/sites/seniorshhealthknowledgenetwork.ca/files/ACB_Anticholinergic_Burden_List_.pdf)

### [Benzodiazepines: List of Trade Names, Uses and Dosage](#)

At <http://www.uatests.com/drug-information/benzodiazepines-list.php>

### [List of benzodiazepines](#)

At [https://en.wikipedia.org/wiki/List\\_of\\_benzodiazepines](https://en.wikipedia.org/wiki/List_of_benzodiazepines)

### [Alternatives for Medications Listed in the AGS Beers Criteria for Potentially Inappropriate Medication Use in Older Adults](#)

A 2-page Tip Sheet from the Health in Aging Foundation.

Download at [http://www.healthinaging.org/files/documents/tipsheets/BeersAlternatives\\_2015.pdf](http://www.healthinaging.org/files/documents/tipsheets/BeersAlternatives_2015.pdf)

### [Avoiding Overmedication and Harmful Drug Reactions](#)

A 2-page Tip Sheet from the Health in Aging Foundation.

Download at [http://www.healthinaging.org/files/documents/tipsheets/Tip.Avoiding\\_OverMedication.pdf](http://www.healthinaging.org/files/documents/tipsheets/Tip.Avoiding_OverMedication.pdf)

### [Ten Medications Older Adults Should Avoid or Use with Caution](#)

A 2-page Tip Sheet from the Health in Aging Foundation.

Download at [http://www.healthinaging.org/files/documents/tipsheets/meds\\_to\\_avoid.pdf](http://www.healthinaging.org/files/documents/tipsheets/meds_to_avoid.pdf)

## [Diez Medicamentos que las Personas Mayores de 65 Años Deben Evitar o Usar con Precaución](#)

A 2-page Tip Sheet in Spanish from the Health in Aging Foundation.

Download at

[http://www.healthinaging.org/files/documents/tipsheets/meds\\_to\\_avoid\\_spanish.pdf](http://www.healthinaging.org/files/documents/tipsheets/meds_to_avoid_spanish.pdf)

## [What to Do and What to Ask: If a Medication You Take is Listed in the Beers Criteria for Potentially Inappropriate Medication Use in Older Adults](#)

A 2-page Tip Sheet from the Health in Aging Foundation.

Download at

[http://www.healthinaging.org/files/documents/tipsheets/Tip.WhatToDoBeers\\_Sept2015.pdf](http://www.healthinaging.org/files/documents/tipsheets/Tip.WhatToDoBeers_Sept2015.pdf)

## **Resources to Learn More about Managing Medications**

### [MyMedSchedule](#)

<https://secure.medactionplan.com/mymedschedule/index.htm>

### [Simplify My Meds](#)

<http://www.lbda.org/content/simplify-your-medicines>

### [Oral Dosage Forms That Should Not Be Crushed](#)

<http://www.ismp.org/Tools/DoNotCrush.pdf>

### [Check My Medicine](#)

<http://www.swallowingdifficulties.com/check-my-medicine>

### [My Personal Medication Record](#)

[http://www.aarp.org/health/drugs-supplements/info-2007/my\\_personal\\_medication\\_record.html](http://www.aarp.org/health/drugs-supplements/info-2007/my_personal_medication_record.html)

## Resources to Learn More about Non-pharmacological Approaches

Massage therapy

<http://www.lbdtools.com/massage.html>

<http://www.khca.org/files/2014/10/Therapeutic-touch-and-accupressure.pdf>

Music therapy

<http://lewybodydementia.blogspot.com/2013/05/the-value-of-music-with-dementia.html>

<http://www.todaysgeriatricmedicine.com/news/story1.shtml>

Pet therapy

<http://www.khca.org/files/2014/10/Animal-Therapy.pdf>

<http://alzheimersproject.org/About-Us/News-Photos-and-Calendar/Latest-News/Pets-and-Dementia>

Art therapy

[http://www.lbdtools.com/art\\_therapy.html](http://www.lbdtools.com/art_therapy.html)

[http://ccn.upenn.edu/chatterjee/anjan\\_pdfs/Chancellor\\_ArtTherapy\\_AD\\_JAD.pdf](http://ccn.upenn.edu/chatterjee/anjan_pdfs/Chancellor_ArtTherapy_AD_JAD.pdf)



# Endnotes

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