

A Lewy Body Dementia Trainer's Kit

Trial Version

The Whitworths of Arizona

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While the information and opinions provided here are believed to be accurate and sound, based on the best judgment available to the authors, staff and families who fail to consult appropriate health authorities assume the risk of any injuries to their patients or themselves.

A Lewy Body Dementia Training Kit, Trial Version

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Full Version also includes:

Staff Training, Part 2 and Family Program

General Guidelines

1. **Length of time for each presentation is approximate** and will vary with the presenter and the number of additions or changes made.
2. **The CD: The Lewy Body Dementia Trainer's Kit CD** contains:
 - ♦ A menu with a self-starting slideshow for each program.
 - ♦ A printable evaluation form for optional use.
3. **The Manual: Contains a unique Read and Click script for each program.**
 - ♦ **Follow the script word for word until you learn how the animations work.**
Once you learn the Read and Click process, feel free to use your own words and stories.
 - ♦ **The words on the slides and the words in the script are often different.**
Your students don't need you, if all you do is read what they can already see.
 - ♦ **Read and Click scripts** have two columns:
 - a) **An information column** contains:
 - the slide number in a large font for easy identification while talking,
 - corresponding textbook pages and
 - earlier slides with information about the same topic.
 - b) **A content column** in Read and Click format, with these features:
 - **Bolded and Underlined words** tell you to “click here.”
 - **(Click to next slide)** tells you to advance to the next slide.
 - *Italicized words are* comments for the narrator’s eyes only.
 - Questions are in this font.
 - i. In the middle of a slide, they usually require only short responses or nods.
 - ii. At the end of a slide, they encourage audience participation. Use or not, depending on time available.

7. **The Textbook, Riding a Rollercoaster with Lewy Body Dementia** by Helen and James Whitworth.
 - ◆ References to pages in the textbook appear in the script Information column.
 - ◆ The back of the book contains resources for the information in these programs.
 - ◆ Minimum number of books: One for the trainer and one in the facility library.
8. **Preparation will make you more effective.** This is a LIVE presentation; not a video you just plug in. As with any live presentation, **preparation is key.**
 - ◆ **Know your subject. Learn about LBD:**
 - a) Read the book.
 - b) Go to lbda.org. Review their literature and browse their forums.
 - ◆ **Become comfortable with the Read and Click format.**
 - a) Practice breeds confidence. Practice the entire program **at least twice** and at least once out loud. You will notice things you missed when you were reading silently.
 - b) Practice so that you can:
 - Synchronize words in the script and special screen animations.
 - Watch both script and screen. It is easy to forget to click, or to click twice and then the script and screen are out of synch.
 - ◆ **Do a run-through of the physical setup.** Prior to a presentation, make sure all of the activities in the next three sections of these guidelines can be performed by you or other staff members.

9. **Setting up is simple:**

- ◆ Connect your computer to projector or TV with the appropriate cable and set the controls for "Dual Display." (See Technical Information)
- ◆ Insert the CD. The menu will come up automatically.
- ◆ Click on the Rollercoaster icon for the presentation you want to show. The title slide will appear. Your first click starts a re-coloring sequence to play while you finish setting up. You can click back to restart it several times if you like.

10. **For the PowerPoint challenged:**

- ◆ If you have not used a wireless mouse for presentations, practice using it in your hand (**not on a mouse pad**). This allows you to move around and talk. To animate the slides, scroll the wheel forward and back. If that is too difficult, use the buttons.
- ◆ If you are not used to reading a script while working the slides, remember that you need to watch BOTH the script AND the slides to keep them synchronized.
- ◆ If the menu does not automatically appear when you insert the CD, go to My Computer, click on the DVD drive named "Whitworth," and choose "play.bat" to start the autoplay.

11. **Technical Information:**

- ◆ Connect your laptop computer to a large monitor (TV or projector and screen) with an S-video or VGA cable. (Either will work if there are ports available.)
- ◆ If using a television for display, adjust its controls to display the appropriate input.
- ◆ Find the controls for display monitor adjustments in your Control Panel. (Name varies with the computer and the programs on it.)
- ◆ Choose Multiple Display, then Dual Display Clone, with Notebook as Primary. (You can choose this ONLY if you already have a second display unit attached.) Click OK and you should see the computer screen on the TV or projector screen.

Staff Training Program

(Trial Version)

Read and Click Script

The Staff Training program is in two half-hour segments.

(This Trial Version contains the *complete Part 1* but does not contain Part 2.)

Try to hold the two trainings no more than a month apart to maintain continuity.

Part 1

<p>1</p>	<p><u>(Run this slide while</u> <i>you are setting up and people are coming in. You can back it up and start the re-coloring sequence over and over.)</i></p> <p><i>First introduce yourself if needed and tell the audience of your own connection with LBD.</i></p> <p>Caregivers say that living with Lewy is like “riding a rollercoaster.” As we go along, you’ll see why that is so. This program was developed by the Whitworths of Arizona who have also written a book by the same name.</p> <p><u>(Click to next slide)</u></p>
<p>2</p> <p>Page 5</p>	<p>We have copies of the book here (<i>hold one up for students to see and say where they are kept</i>) for you to check out and read (<i>or buy if that is so.</i>) Don’t wait until you have a patient that is diagnosed with LBD to read it. The more you know about this disease, the more you will recognize it—often in patients who are diagnosed with something else. LBD is often misdiagnosed and people can have more than one form of dementia.</p> <p><u>(Click to next slide)</u></p>

<p>3</p>	<p>This program comes in two parts. The first one is about the LBD family, the dementia aspects of LBD, and treatment. The second is about LBD's non-cognitive symptoms, the very serious problems with LBD and drugs, and finally, your importance as LBD caregivers.</p> <p><i>(Let them know if you will be covering both parts today, and if not, when you will cover the second part.)</i></p> <p><u>(Click to next slide)</u></p>
<p>4</p>	<p>Before we go further, I'd like to introduce you to some people who will show up occasionally in this presentation. When Annie had LBD, doctors knew very little about the disease and she was treated as though she had Alzheimer's. <i>(Annie is "Anique (An-neek)" in the textbook.)</i></p> <p><u>When Bill was</u> diagnosed, doctors knew more, but still not enough. He and Barb traveled from Alaska to Florida in their motorhome teaching about LBD.</p> <p><u>Lucille died before</u> she had any cognitive symptoms of LBD, but she did have some non-cognitive symptoms.</p> <p><u>A female and in</u> her late 60's, Dorothy fits the profile for someone with Alzheimer's. More women than men suffer from AD.</p> <p><u>(Click to next slide)</u></p>

<p>5</p> <p>Page 8</p>	<p><u>Both Lewy body</u> dementia and <u>Parkinson's disease</u> are <u>caused by Lewy</u> bodies in the brain.</p> <p><u>(Click to next slide)</u></p>
<p>6</p> <p>Page 8</p>	<p>Lewy bodies are <u>damaged proteins</u> that collect in the brain cells. See the little round spot in this photo?</p> <p><u>They weaken</u> and kill the cells by extracting certain chemicals.</p> <p><u>(Click to next slide)</u></p>
<p>7</p> <p>Page 9</p>	<p>When Lewy bodies reside in <u>the cortex of the</u> brain, <u>We see</u> dementia symptoms.</p> <p><u>This is called</u> Dementia with Lewy bodies.</p> <p><u>That's what</u> Jim Whitworth's first wife, Annie had.</p> <p><u>(Click to next slide)</u></p>
<p>8</p> <p>Page 9</p>	<p>When Lewy bodies reside in <u>the mid-brain,</u> <u>We see motor</u> problems.</p> <p><u>We call that</u> Parkinson's disease.</p> <p><u>That's what</u> Helen Whitworth's sister, Lucille, had.</p> <p><u>(Click to next slide)</u></p>

<p>9</p> <p>Page 9</p>	<p>Parkinson's disease includes the following motor symptoms.</p> <p><u>The first</u> noticeable symptom is most likely a tremor.</p> <p><u>PD can be</u> a younger person's disease. Michael J Fox was 30 when he was diagnosed.</p> <p><u>Many people</u> with PD go on to develop dementia. The difference in percentages is that it increases with age.</p> <p><u>(Click to next slide)</u></p>
<p>10</p> <p>Page 9</p>	<p><u>What symptoms</u> would you see when Lewy bodies are <u>in both areas</u> of the brain?</p> <p><u>Yes, both dementia and</u> motor problems.</p> <p><u>We call this</u> Parkinson's disease with dementia</p> <p><u>And that</u> is what Bill had.</p> <p><u>(Click to next slide)</u></p>

11 <i>Pages 11-12</i>	<p>When we talk about these dementias, we need to discuss definitions. First there was just dementia with Lewy bodies. And people used the terms <u>“Lewy body dementia”</u> and “dementia with Lewy bodies” interchangeably. They meant the same thing.</p> <p><u>But then</u> in 2006, the experts added Parkinson’s disease with dementia to the family.</p> <p><u>They agreed</u> that both dementias have same cause and the same cognitive symptoms. That’s when the definition for LBD changed:</p> <p><u>It is now an</u> umbrella term for both types of dementia.</p> <p><u>Notice that</u> DLB starts with a D for dementia and that’s the way the disorder starts—with dementia.</p> <p><u>PDD starts</u> with a P for Parkinsons and that’s the way it starts--with Parkinson’s.</p> <p><u>(Click to next slide)</u></p>
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12 <i>Pages 14-16</i>	<p>It would be great if we could just do a test and see what kind of dementia a person has.</p> <p><u>As it is, most</u> people are diagnosed with something else before they are diagnosed with LBD.</p> <p><u>That's because</u> a diagnosis is based on a doctor's assessment and thus dependant on that doctor's knowledge of LBD.</p> <p><u>A thorough</u> explanation of the diagnostic criteria is in your LBDA brochure. By the way, this brochure is so thorough, that it could be called the Cliff Notes for LBD.</p> <p><u>But just quickly,</u> DLB and PDD have similar diagnostic criteria</p> <p><u>except that PDD</u> patients will have had motor problems first.</p> <p>Can you think of any of your Parkinson's patients who have developed dementia?</p> <p><u>(Click to next slide)</u></p>
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13

Pages
4-6

Re: #2

Remember Dorothy? She has Alzheimer's. How many of you have heard people say, "I thought that Alzheimer's and dementia were the same?" Well, Alzheimer's is the most common dementia, and they'd be right at least 50% of the time.

But there are many more. Can anyone guess how many kinds of dementia there are? (*Answer: Over 70*)

Today we are talking about Lewy body dementia.

There are over 1.3 million people in the US with LBD.

Remember that people can have more than one dementia at a time.

And so Dorothy could also have LBD. This is important to know because it's LBD that causes serious problems with drugs, not AD.

(Click to next slide)

14 <i>Pages 4-6</i>	<p>Another common statement is “There’s Alzheimer’s, and then there’s dementia.” Well, you now know that there are far more than two kinds of dementia. But what does “dementia” really mean? <i>Take a few answers and then go on, using what’s been said as well as you can..</i></p> <p><u>That’s close.</u> The dictionary definition is “The loss of two or more cognitive functions.” When talking about LBD, we prefer to say</p> <p><u>the decrease of</u> functions because as you will see, LBD patients seldom lose their cognitive functioning entirely.</p> <p><u>These are all</u> cognitive abilities. How many are you using right now? <i>(Answer: All of them)</i></p> <p><u>(Click to next slide)</u></p>
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15

Pages
4-6

One difference between AD and the cognitive symptoms of LBD is how they first show up.

Dorothy's dementia showed up first as a **memory loss**. She describes it as “My rememberer is broken but my forgetter is very good.”

Bill's showed up as a difficulty with **executive tasks**. His first noticeable symptoms were making bad decisions and odd choices.

If your patient remembers your name from day to day but does things like brushing their teeth and *then* putting the toothpaste on the brush, what kind of dementia might they have? (*LBD—tooth brushing is a sequential task, with steps that must be done in order.*)

As the dementias progress,

these differences will be blurred, because advanced dementias become similar as more and more brain cells die.

However by then, distinctive non-cognitive LBD symptoms will have appeared. These tend to cause the acting-out behaviors. We'll discuss these in Part 2.

(Click to next slide)

16 <i>Pages</i> 4-6	<p>People with LBD have memory losses too, but they start differently:</p> <p><u>Dorothy would</u> say things over and over. But she could still play old tunes on the piano.</p> <p><u>That's because AD</u> causes her to have problems TRANSFERRING info from her short term to her long term memory.</p> <p><u>Annie had</u> trouble ACCESSING info from her long term memory. For instance,</p> <p><u>she had been</u> a good cook, but early on she lost the ability to do this. However,</p> <p><u>she could usually</u> remember what was just said.</p> <p><u>(Click to next slide)</u></p>
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17 <i>Pages</i> 4-6	<p>Here are some other differences:</p> <p><u>All dementia</u> patients tend to have slow thought processes, but <u>Dorothy still</u> could talk fairly well.</p> <p><u>A combination of</u> slow thought processes and poor fluency made talking difficult for Annie and Bill.</p> <p><u>Dorothy's general</u> health is still good.</p> <p><u>Both Annie and Bill</u> had severe health challenges, due to the non-cognitive aspects of LBD.</p> <p><u>All dementia</u> patients tend to have poor impulse control, <u>but LBD's behavioral</u> symptoms make it much more noticeable.</p> <p><u>(Click to next slide)</u></p>
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<p>18</p> <p><i>Pages 23-25</i></p>	<p><u>Fluctuating Cognition</u> is a defining symptom of LBD -- a symptom that appears in LBD but is uncommon in other diseases.</p> <p><u>Alzheimers causes</u> Dorothy's cognition to make a gradual but steady downhill decline.</p> <p>LBD causes cognition to decline over time too, but it has more of what caregivers sometimes <u>call a rollercoaster effect</u> like this.</p> <p><u>Physical and</u> motor issues can also fluctuate. For instance, most of the time Bill could barely walk, but sometimes he had no trouble walking.</p> <p><u>Caregivers talk</u> about their loved one's Bad Times, Good Times and Showtimes.</p> <p><u>(Click to next slide)</u></p>
<p>19</p> <p><i>Pages 25-26</i></p>	<p>The Bad Times are when the dementia is present.</p> <p><u>At first there</u> are only isolated instances of "odd" behavior or confusion.</p> <p><u>By the time</u> a patient needs your help, this behavior is likely to be the norm.</p> <p><u>But the patient will</u> still have periods of awareness.</p> <p><u>(Click to next slide)</u></p>

20

Page
24

We call these the Good Times.

Often the pattern will be that a patient is more alert in the morning or after they've had a nap.

They will be more able to help with their daily care, **and this is the** time to tell them anything you want them to know. For instance, if you are planning to move your patient to a different room, tell him during a Good Time. He may not remember what you said, but he will be more accepting of the move.

These periods of better awareness never disappear entirely.

For example, it's not unusual for an LBD patient to recognize family members even on their deathbed.

If you saw an LBD patient eating well one day and unable to handle his spoon the next, would you encourage him to try anyway, or help him?

Right! You'd help him. He's NOT FAKING.

(Click to next slide)

21

Pages
25-26

Showtimes are perhaps the most difficult.

This is when a patient appears alert in the presence of someone other than their regular caregivers.

It's important to remember that they have no control over these fluctuations.

This can be a problem for doctors because they need to know what the patient's behavior is really like to treat it properly.

It can be a concern with visiting relatives. If you've been telling the family that your patient is becoming more difficult and then when they come to visit, the patient is "just fine," the family may believe you are the problem, not their loved one,.

Therefore, your nursing notes become an important tool for identifying patterns and showing actual behavior.

Can you think of a patient who seems much more aware at some times than at other times?

(Click to next slide)

<p>22</p> <p><i>Pages 30-43</i></p> <p><i>(See next slides for specific pages)</i></p>	<p>LBD has many other symptoms besides the cognitive ones we've been discussing.</p> <p><u>Sleep disorders</u> often appear many years before the cognitive symptoms do.</p> <p><u>Physical problems</u> are the ones that take up much of a caregiver's time.</p> <p><u>Perceptual problems</u> and behavioral issues can make LBD look like a psychiatric disease but it reacts very poorly to psychiatric meds.</p> <p>We'll cover all of these in Part 2.</p> <p><u>(Click to next slide)</u></p>
<p>23</p>	<p>Treatment for LBD is the same as it is for any other dementia: <u>Dementia drugs</u> and <u>Encouraging a</u> healthy life style. <i>(Allow a few seconds for students to see photos of healthy living.)</i></p> <p><u>(Click to next slide)</u></p>
<p>24</p> <p><i>Pages 49-50</i></p>	<p>These dementia drugs have been used to treat AD for years. <u>Research has</u> shown them to be even more effective with LBD.</p> <p><u>No drug will</u> cure dementia, they just slow it down.</p> <p><u>These drugs</u> need live cells to work. As the disease kills the cells, they become less effective.</p> <p><u>(Click to next slide)</u></p>

25

*Pages
51-52*

There's also a balance issue with these drugs.

LBD requires constant monitoring and adjusting of medications. Often a drug given for one problem can cause another. That's the case with PD meds and cognition meds.

Drugs given for PD can increase dementia.

Likewise, dementia drugs can increase movement problems.

The good news is that in both cases, the symptoms are temporary—that is they leave when the drug leaves the body.

Families must continually make decisions concerning mobility and cognition.

They usually opt for more awareness, even when the workload is more.

Have you ever noticed a patient become more confused after his PD meds had been increased?

How about someone who had mobility problems after an increase in dementia drugs?

(Click to next slide)

<p>26</p> <p><i>Pages 44-47</i></p>	<p>A healthy life style delays dementia or, once present, slows it down. This includes a healthy diet, <u>with lots of</u> fruits and vegetables. Instead of TV, encourage <u>mental challenges</u> such as puzzles and games. Dementia increases isolation. Fight it by encouraging <u>socialization</u>. Notice that socialization often includes other aspects of a healthy lifestyle as well.</p> <p><u>(Click to next slide)</u></p>
<p>27</p> <p><i>Pages 45-46</i></p>	<p><u>Experts say that</u> exercise is a better dementia treatment than any drug.</p> <p><u>It's especially important</u> for the LBD patient because exercise is related to executive abilities—the ones a person with LBD lose first.</p> <p><u>Exercise also reduces</u> depression, improves health and just plain makes you feel better.</p> <p><u>To be done right</u>, exercise should be regular.</p> <p><u>It should be</u> fitted to the individual's needs. For instance, dancing is great exercise because it also includes mental stimulation and socialization, but not everyone can do it.</p> <p><u>However, you</u> can usually find something a person can do, such as these chair exercises.</p> <p><u>And finally</u>, it should be fun, like fishing is for this guy with his walker.</p> <p><u>(Click to next slide)</u></p>

<p>28</p> <p><i>Page 24</i></p>	<p>As important as exercise is, LBD caregivers say socialization with their loved one is what they miss most. This part of this program ends with a poem about a Good Time that brought a little taste of what used to be. <i>(Read the poem line by line as it comes up.)</i></p> <p><u>Yesterday I had</u> a chance encounter with an old flame He was every bit as charming as I remember And I was so glad to see him. We had dinner together and talked About everything and nothing at all. It made me feel young again and yes, I even flirted a little. It was just so nice to spend an evening being “normal.” I don’t recall exactly when he left. I just looked up and John was gone And Lewy had returned. <i><u>(Click to next slide)</u></i></p>
<p>29</p>	<p>Thank you for attending. Part Two is scheduled for <i>(date and time)</i>. <i><u>(Click twice to</u></i> return to the menu or click once, and hit "escape" to end the program.)</p>

NOTES: