



Live Chat Event with Dr. Stephen Gomperts, MD

March 28, 2007

**Victoria Ruff
(Moderator)**

Welcome to this evening's LBDA online chat event. Our guest is Stephen N. Gomperts, MD, PhD. He is the Assistant in Neurology at the Memory and Movement Disorder Unit (MMDU) at Massachusetts General Hospital and Research Fellow at Picower Institute for Learning & Memory at Massachusetts Institute of Technology.

The MMDU is an integral part of the Massachusetts Alzheimer's Disease Research Center and is a part of Udall Parkinson's Disease Research Center for Excellence. Dr. Gomperts' clinical and clinical research focus is on the cognitive and behavioral problems that arise in neurodegenerative disorders, with particular emphasis on dementia with Lewy bodies and Parkinson's Disease. His basic science focus is on the role of the dopamine system in learning and memory.

Dr. Gomperts

Thank you for the opportunity to meet with you. I have to preface my response to these questions by saying that without actually evaluating your loved ones and speaking with each of you in detail, i.e. without knowing much more than we can cover in a chat session, I cannot provide specific medical advice for a given individual patient. I will therefore attempt to answer your questions in generic terms.

I also need to preface by stating that I have no personal benefit in any of the recommendations that I make below (e.g. medications), and my recommendations are only recommendations.

**Victoria Ruff
(Moderator)**

As a reminder, the questions that were emailed to the Victoria Ruff, Moderator will be posed first. Should time permit, the board will be open for additional questions to Dr. Gomperts.

Please note that some questions that were emailed can't be answered completely since Dr. Gomperts doesn't know your loved one's history, examination and work-up.

Another reminder: **The information presented during the Online Chat is for informational and educational purposes only and is not intended to substitute the professional medical advice or treatment recommendations provided by your loved one's doctor.**

Without further ado, let's get to the questions.

1. Question from Norma: A person who has been off of Reminyl and Namenda for 4 months and who, in the last 2 months has declined significantly (loss of weight, ability to walk or stand, and whose cognition has changed) could Exelon or Aricept help a little now? She's 84 years old.

Dr. Gomperts

Again, without evaluating your loved one to exclude reversible causes of decline (including, for example, electrolyte imbalance, thyroid disorder, medication side effects, etc), I cannot comprehensively speak to your particular problem. So I will speak generally. Unfortunately, as I believe you may know, we presently have no medicine that treats the underlying cause of dementia with Lewy bodies (DLB) or Parkinson Disease dementia (PDD) (I will refer to both together as Lewy body dementia (LBD) from here on). Instead, we have in our arsenal medicines that treat the symptoms of the disease. But the disease progresses relentlessly while we treat the symptoms. Many medical scientists are working on this problem, with a goal of stabilizing or even reversing the disease, but we're not there yet.

Many patients respond (to varying degree) to acetylcholine esterase inhibitors (the class of medicines that include Reminyl, Exelon, and Aricept). While some patients can have a remarkably robust response, it can be subtle at best in other patients. Although there are fewer studies out there on Namenda (memantine), similar variability of response across people is likely to be true as well.

Because patients with DLB tend to get worse over time, these medications may only lead to a temporary stabilization in symptoms (or even a decline in the rate of progression). But that's still a worthy goal.

The lack of a robust response is one reason why these medications are discontinued. Another would be a side effect. Without knowing why Reminyl and Namenda were discontinued for your family member, it's a little hard for me to answer your question.

Broadly speaking, yes, it would be reasonable to try other agents. These agents are generally well tolerated, and if one causes a side effect, there is still a reasonable chance that another will not.

**Victoria Ruff
(Moderator)**

2. Question from Sue: My spouse becomes anxious when left alone in a room. He knows where I am yet, he will shadow me around the house or constantly call for me to come back into his sight or escalate his agitation to draw me off task and back to him. I've given him Klonopin - 0.5 or 1.0 mg but it seems to increase confusion. How can I decrease his anxiety when I need to move about the house?

Question from Phyllis: Are there any safe medications for anxiety or irritability for LBD patients since they seem to be so sensitive to medications in general?

Dr. Gomperts

Medicines like Klonopin (the benzodiazepine class) often cause confusion in the elderly as well as in patients with dementia. In my opinion, they are better left out of a medication regimen for a patient with LBD. Many patients with LBD are exquisitely sensitive to medications. That makes medical treatment a real challenge.

On the whole, I advocate for minimizing and streamlining the medication regimen; stripping away every unnecessary agent. That reduces the probability of medication side effects and medication interactions.

When a medication is required, my recommendation is to start low (dose) and go slow (titrate up slowly as necessary). Non-medication approaches are certainly worthwhile, and include reassurance and occupying him with something to do while you leave the room.

**Victoria Ruff
(Moderator)**

3. Question from Donna: What should caregivers do when loved ones won't sleep?

Question from Bobbi: Are any meds being investigated to alleviate sleeplessness in LBD patients?

Question from Marcia: SLEEP how do you get them to sleep, so that we caregivers can get some sleep, too.

Dr. Gomperts

Let me finish a quick thought about anxiety.

As I stated above, I try to avoid prescribing medications to DLB patients unless absolutely necessary. When necessary, however, there are some agents that can help. One group that should not be overlooked is antidepressants (like the SSRIs or NSRIs). Each is a little different, and some, like Effexor, seem to have some anti-anxiety properties.

Antipsychotics like Clozaril (clozapine) or Seroquel (quetiapine) can also help, but I would reserve their use for severe cases.

As you may know, there's currently a hot debate about the safety of that class of agents, so to use one of them in a given patient's circumstances, their potential benefits have to outweigh their risks.

Another good (and hard) question. Sleep problems are common in LBD. Patients often sleep during the day (many for more than 2 hours total), and that can lead to nighttime wakefulness. This can even lead to full-blown sleep-wake reversal.

Dr. Gomperts

This can be hard to treat. One thing to do is to try to minimize daytime naps, as possible, to help the patient return to a nighttime sleep pattern. It is also important to have your loved one's doctor review his medications, to check whether some of his night-time dosed medications may in fact be activating him, and if some of his morning/day time medications may be contributing to daytime somnolence. If that's the case, it may be possible to move the activating medications to morning, and the sleep-enhancing medications to night.

Another approach would be to substitute in an otherwise equivalent medication for another to provide more morning activation or more nighttime sleepiness. Sleep medications like benzodiazepines can cause confusion, and should be avoided.

An antidepressant that provides a little sleepiness, however, may be worthwhile.

**Victoria Ruff
(Moderator)**

4. Question from Sue: My husband quickly becomes agitated then displays generalized anger when ever I get a phone call lasting more than a minute or two. What is causing this? A need to control the caregiver?

Question from Bobbi: Are any meds being investigated to alleviate agitation in LBD patients?

Question from Phyllis: Do LBD patients usually get as aggressive as the disease progresses?

Question from Marcia: AGITATION and/or AGGRESSION: What's the best medication to control this?

Dr. Gomperts

The systems that hold emotions in check and inhibit us from “behaving badly” can progressively deteriorate in LBD. As a result, some but not all patients develop progressive agitation or aggression as the disease proceeds.

It is not clear why Sue’s husband is acting the way he is. There are many possibilities. As you know him well (and I do not know him at all), your interpretation may well be better than mine.

Here are a few of the many possibilities: Certainly it could be a demand for your undivided attention.

Perhaps your speech or interactions provide him with something that he likes. Perhaps you occupy him, and when unoccupied, he transitions into agitation.

It is worth keeping in mind that an unusual amount of agitation for a patient with DLB (i.e., a change from baseline) may reflect a problem (like pain or discomfort) that the patient is unable to articulate.

Dr. Gomperts

Once those problems have been ruled out (or treated), and we are left with the stereotyped agitation that can arise in LBD, again I think it is better to try non-medication based treatments first. If severe, however, the antipsychotics Seroquel and clozapine are useful and can often help with agitation.

As I talked about above, their use has been implicated in shortening life span; it was a small effect in one study (not seen in several other evaluations), and is a hot topic of debate at the moment.

We do not know for certain that these medications are harmful in the long run, but they may be. However, at some point agitation and aggression can get severe enough to warrant their use.

That is a decision for you, your doctor, and your loved one to make. I should also add that clozapine requires weekly blood tests to ensure against a serious but very rare possible side effect called agranulocytosis.

**Victoria Ruff
(Moderator)**

5. Question from Sue: In periods of delusional activity, is it best to orient the patient back to reality?

Question from Donna: Is there a way to stop the hallucinations?

Question from Imogene: Does a person's TV habits (i.e.; violent or love story movies) have any bearing on the type of hallucination they may have?

Question from Marcia: HALLUCINATIONS: Again, what is the best medication, to date, to control the hallucinations?

Dr. Gomperts

Some medications for the parkinsonism (tremor, rigidity, motor slowness, impaired balance) of LBD can cause hallucinations. It would therefore be important to minimize all medications that can cause hallucinations (while still optimizing motor treatment).

Infections or electrolyte imbalance (and rarer problems like alcohol withdrawal or toxic ingestions, etc) can also contribute and need to be ruled out. If hallucinations persist, however, as they often do in LBD, then treatment with medication needs to be considered.

The antipsychotics Seroquel and clozapine are effective medications for hallucinations - and also for delusions. Clozapine may be a little better, yet another contentious topic in the medical literature. I've talked about their risks above.

I strongly avoid all other antipsychotics, as they can produce severe side effects in patients with LBD, including, notably, severe worsening of parkinsonism.

Dr. Gomperts

Some hallucinations are pleasant or neutral (like seeing family members in the living room), while others are scary and upsetting and provoke agitation. I treat the latter type, and leave the former type alone.

I am not aware of any studies looking at whether TV (or other behavioral) habits could influence the nature of the hallucination experienced, and I would be guessing if I tried to answer your question about TV.

Reorienting can help with modest hallucinations, for example in mild, early disease, in large part because the patient retains insight into their hallucinations and is able to understand and be reassured by the information that the hallucination they are experiencing is not real.

That becomes much more difficult if the patient has significant cognitive impairment. In a delusion, a patient has a false, fixed idea about something that is not real. Persuasion in that setting is very unlikely to convince them otherwise.

**Victoria Ruff
(Moderator)**

6. Question from Pat: I have a question about the hallucinations. My spouse has them all of the time but only at our house both outside and inside. He has had them for about a year, and they keep getting more severe. Is that a sign that he is getting worse? He is on medication, but he still sees them.

Dr. Gomperts

The fact that his hallucinations are getting more severe suggests that your spouse may be slowly getting worse, unless his hallucinations can be explained by his taking increasing doses of Parkinson medications (like dopamine agonists) or other medications that can cause hallucinations as a side effect.

Again, I do not aggressively treat hallucinations unless they cause trouble. It sounds like they may be causing trouble for your husband, but that is unclear. Is the medication that you refer to an antipsychotic agent (also known as a neuroleptic)?

If so, antipsychotic agents are more effective at higher doses, so there may still be some room to go with his medication, though increases should be gradual and careful.

If there is no benefit once a given medication dose is maximized, his doctor may consider trying a different antipsychotic medication.

**Victoria Ruff
(Moderator)**

7. Question from Anita: Many times our loved ones complain of perceived medical problems or simply not feeling well in certain areas. For instance my loved one constantly complains of something being wrong with his system meaning he thinks he needs to go to the bathroom and can't, etc, etc. It has gotten so bad at times that I take him to the Doctor and they run expensive tests only to find out that nothing is wrong. Is there any special things that we should look for in our LO in order to determine if a further look is necessary? Are there any real guidelines to go by for us to know if seeing the Doctor is in order considering the constant complaints we get from our loved ones?

Dr. Gomperts

Many patients with LBD have trouble communicating, and that can lead to all sorts of difficulty when they don't feel well. As a result, it can be hard for his doctor to identify whether there is a problem, and it can be hard for you as well.

Unfortunately, there is no single thing for you or his doctor to look for to know that something is or is not wrong.

Certainly, a change from prior behavior/function raises concern, e.g. a new complaint, or a more severe old complaint, or a change in behavior (e.g. suddenly more quiet and subdued), or the obvious signs of true illness, like fever, cough, etc.

However, it's good to be vigilant. So if you are concerned, I would bring him in to his doctor for an evaluation. Over time, with experience, I suspect that you will develop a good sense about when he is ill and when he is not really ill. I wish it were easier.

**Victoria Ruff
(Moderator)**

8. Question from Imogene: Has anyone experienced a LO with a problem for eleven years? (My husband couldn't do math in 1995. He quit his job because of it. He soon forgot all the phone numbers in his head, and messed up the checkbook. In 2005, he was diagnosed with Lewy Body Dementia. He is still considered early stage.) Did he actually have it that long?

Dr. Gomperts

Without seeing your husband in clinic, speaking with you both in detail to review his history, examining him, and reviewing his evaluation, I cannot provide a firm medical opinion about his diagnosis. The course (duration of disease) of DLB does vary significantly across individuals.

That said, 12 years is an extraordinarily long time to carry early stage DLB, and it is possible that he may not have DLB, or may not have DLB in isolation. (One can develop new cognitive problems after many years of Parkinson Disease, and they can progress over time, but that does not fit the history that you gave me.)

**Victoria Ruff
(Moderator)**

9. Question from Claudia: Can the REM Sleep Disorder in LBD mean lack of all dreaming, or is that an indication of another illness?

Dr. Gomperts

I am not sure that I fully understand your question. REM sleep behavioral disorder (RBD) is an abnormality of REM sleep. In REM sleep, we dream but are normally unable to move (in fact, we're paralyzed). In REM sleep behavioral disorder, the paralysis is lost, so patients act out their dreams. RBD is common in LBD but is not always present.

RBD is also common in Parkinson Disease. (Many people wake up from sleep unable to remember their dreams. That by itself is not concerning for an illness.)

**Victoria Ruff
(Moderator)**

10. Question from Victoria Ruff, Moderator and Donna: I understand that everyone is different and reacts differently to meds, but what would your first med of choice be for the following LBD symptoms:

- Cognition/Dementia?
- Depression?
- Parkinsonism?
- Hallucinations?
- Anxiety?
- REM Sleep Disorder?
- Excessive Daytime Somnolence?
- Restless leg syndrome (RLS)?
- Orthostatic Hypotension?
- Insomnia?

Question from Bobbi: Are any meds being investigated devoted to LBD symptoms?

Dr. Gomperts

This is a hard question, exactly because everyone is different, and because the medical problems that they have and the other medications that they are on can affect a doctor's medication recommendations. However, you've asked me to ignore the complicating factors.

I want to again stress that it's better to minimize medications, rather than having one medication for each of these problems and thereby creating a set-up for "polypharmacy".

My first choices are: Cognition/dementia: Aricept, Exelon, or galantamine, as tolerated. (Also attempt to discontinue all medications that can cloud thinking; some anticholinergic bladder medications, for example, can cause significant cognitive problems.)

Parkinsonism: Sinemet

Hallucinations: Seroquel (although one can make a compelling case for Clozaril)

Dr. Gomperts

Anxiety: effexor/Seroquel

REM sleep behavioral disorder: This does not always warrant medication for management. If the patient is injuring himself, however, that would certainly drive me to recommend treatment. One option would be melatonin.

EDS: consider a more activating antidepressant and take it in the morning/move sedating medications to night dosing.

Restless Legs Syndrome: Sinemet (can be slow release form if necessary)

Orthostatic hypotension: Ted hose and, if safe for the patient, liberal salt intake (several medications can provide additional help if those maneuvers are insufficient)

Insomnia: consider a more sedating antidepressant and take it at night, and move all sedating medications to night.

That list covers much of the gamut of problems that patients with LBD get, but does not cover so-called “cognitive fluctuations”. Unfortunately, we do not yet have medications directed at the cognitive fluctuations that some patients with LBD get.

**Victoria Ruff
(Moderator)**

I 1. Question from Linda: What sort of pain medications are the best to use for LBDers. I know that hospice tends to use morphine and I have seen that morphine is on the bad drugs list. What are the alternatives?

Question from Bobbi: Are any meds being investigated to alleviate pain in LBD patients?

Dr. Gomperts

LBD by itself does not cause pain. Pain when it arises has to be well treated. If not the patient will be uncomfortable. Secondly, pain may lead to significant agitation. Pain treatment really depends on the problem being treated.

Acetaminophen (Tylenol) and ibuprofen (Motrin) are preferable for mild pain. For more severe pain, Darvocet (Darvon) or Ultram may be preferable to oral opiates. When an IV pain medication is required, the shorter acting the better (as any side effects, such as confusion, may be short lasting).

The bottom line is that effective pain control is critical, and has to be balanced against the need to maximize cognitive function. Unfortunately, the medication sensitivity that is common in LBD can commonly lead to side effects such as confusion. Each patient’s doctor should be happy to discuss medication options with you.

**Victoria Ruff
(Moderator)**

I 2. Question from Sue: Do you have any suggestions for brain exercises to slow down the process of cognitive/ST memory decline in LBD patients?

Dr. Gomperts

Early evidence suggests that cognitive (and gentle physical) exercise may help in Alzheimer’s disease. We do not know for sure that cognitive (and gentle physical) exercise will slow down cognitive decline in LBD, but it’s a real possibility, and cognitive exercises certainly won’t hurt.

I recommend doing anything that is fun for the patient to do, because that increases compliance with the task. Secondly, the more challenging the better.

The exercise to choose depends not just on the patient’s interests but also on his/her level of cognitive function. I tell patients to do what you can. So, if you are able and interested, play bridge or chess, do sudoku, do the *New York Times* crossword, etc. If not, do something a little easier.

The idea is to keep the mind active. It probably does not have to be super heavy lifting.

**Victoria Ruff
(Moderator)**

I 3. Question from Phyllis: Are there any definable stages in LBD as in Alzheimer's?

Question from Victoria Ruff, Moderator: I’ve read in researching online that there were “six developmental stages” found during autopsy, have those “stages” been transferred to note LBD stages that are found during clinical diagnosis and can be shared with the caregivers?

Dr. Gomperts

Physicians currently use a variety of tools to help us with clinical staging of LBD. Clinical stage can be defined along the axes of both dementia and parkinsonism, and is a useful tool for doctors. Mild, moderate, and severe dementia (and mild cognitive impairment) are all reasonable terms that doctors can quantify with rating scales (like the CDR scale).

Several different rating scales exist. The motor impairments of parkinsonism can also be rated, for example using the Hoehn and Yahr scale, which scores involvement of a single side, involvement of both sides, the additional involvement of the midline and balance, and severity of motor impairment thereafter.

Other rating scales exist, too (such as the UPDRS subscale III). One goal in using scales such as these is to tailor treatment to a given dementia and motor stage.

Dr. Gomperts

The six neuropathological stages that have been described at autopsy by Braak and Braak over the last few years describe the location of cells that contain Lewy bodies in the brain of patients with Parkinson Disease (not LBD, per se). In stages 1 and 2, Lewy bodies are found only in the lowest part of the brain (medulla, pons, anterior olfactory structures).

In stages 3 and 4, they spread to involve the adjacent midbrain where the dopamine cells reside (substantia nigra) and to other nuclei of the basal forebrain. These stages are felt to be the likely point at which patients develop the motor symptoms of parkinsonism.

In the final stages 5 and 6, the Lewy body pathology spreads to involve the cerebral cortex (neocortex). One of the Braaks' hypotheses is that the involvement of cells in the cortex may cause the cognitive problems/dementia that arise in dementia with Lewy bodies (DLB) and Parkinson disease dementia (PDD). Many centers are exploring the hypothesis.

If Lewy bodies do prove to be the cause of the disease, then medicines that stop them from forming (or spreading to neocortex) may treat the disease.

**Victoria Ruff
(Moderator)**

14. Question from Bobbi: Why doesn't the doctor who does diagnose LBD inform the caregiver of the wide variety of LBD symptoms and perhaps how to prepare for it?

Dr. Gomperts

I think that it would be reasonable and appropriate for doctors to inform patients and their caregiver of the wide variety of LBD symptoms that can arise. However, different problems can become primary in different patients with LBD, and can manifest at different stages of disease, so it would be hard for your doctor to cover every contingency in terms of preparation.

It is important that once a problem arises, your doctor can work with you and your loved one swiftly to treat it.

**Victoria Ruff
(Moderator)**

15. Question from Pat: My second question is about him perceiving me as someone else exactly like me but negative, and he is difficult when he thinks I am her. It happens like switching on and off a light switch. The switch happens, and I can't see any pattern for it. He sometimes feels he isn't in his house and wants to go home. Any suggestions for dealing with this?

- Dr. Gomperts** These are common delusions, so common that they have names Capgras syndrome for thinking that a loved one has been replaced by an imposter; and reduplicative para-amnesia for thinking that his house has been replaced by an imposter. Sometimes these problems are worse at certain times of day (for example, late afternoon). They are not always easy to deal with.
- Dr. Gomperts** Reassurance and patience are both worthwhile. An antipsychotic agent like quetiapine (Seroquel) or clozapine (Clozaril) may help, and may be warranted if the repercussions of the delusion are severe (e.g. if he gets very agitated).
- Victoria Ruff (Moderator)** 16. Question from Bobbi: Why is the diagnosis of LBD so elusive?
- Dr. Gomperts** It is actually not that hard a clinical diagnosis to make, if there is evidence of parkinsonism, hallucinations, or cognitive fluctuations, along with cognitive decline. The diagnosis may appear elusive because (1) LBD is a relatively new addition to clinical medicine, and (2) Alzheimer's disease is much more common, so that many problems that cause dementia are mistakenly attributed to Alzheimer's disease. The gold standard diagnosis, however, remains looking at the brain at autopsy. We are working to improve the clinical diagnostic criteria.
- Victoria Ruff (Moderator)** 17. Question from Phyllis: Are heart problems and strokes more prevalent in LBD patients?
- Dr. Gomperts** No. Actually they are not.
- Victoria Ruff (Moderator)** 18. Question from Claudia: Why does my spouse seem to experience cognitive difficult around me and no one else?
- Dr. Gomperts** If I understand you correctly (and I may not), I suspect that you may simply be more aware of your spouse's cognitive problems than other people who do not know him as well. If his problems are not too severe, then he may appear normal to people who do not explore too deeply.
- Victoria Ruff (Moderator)** 19. Question from Victoria Ruff, Moderator: Are you researching and getting any positive results with any type of dietary aides / nutritional supplements? For example, we noticed positive results with Alpha Lipoic Acid added to my mom's cocktail of meds.
- Dr. Gomperts** I personally am not. I recently did a search on Medline on this question, and did not find a single study on the topic. Certainly more research needs to be done in this area. Coenzyme Q10 is an antioxidant medicine that seems to help in ALS, another neurodegenerative disease. There is no evidence to date on whether it may help in LBD.
- Victoria Ruff (Moderator)** 20. Question from Imogene: In layman's terms which Dementia of AD and LBD has the tangled neurons, and which has cell death?
- Dr. Gomperts** Alzheimer's Disease has amyloid plaques (deposits of a protein called amyloid-beta outside of and around brain cells) and accumulation of neurofibrillary tangles (composed of a protein called tau) inside brain cells. Many brain cells die as the disease proceeds, including the workhorse cells of the brain as well as cells that make the chemical (neurotransmitter) acetylcholine.

Dr. Gomperts

In LBD, there is accumulation of Lewy bodies (spheres of proteins including alpha-synuclein) inside brain cells. Some brain cells die as the disease proceeds, most notably the cells that make “neuromodulators”, like dopamine and acetylcholine, but there does not appear to be quite as much cell death as in Alzheimer’s disease.

**Victoria Ruff
(Moderator)**

21. Question from Bobbi: Why have so many doctors never even heard of LBD?

Dr. Gomperts

LBD has only recently begun to gather the attention it deserves as the second most common dementia after Alzheimer’s disease. It is now getting better publicized, and more physicians and scientists are studying it, so I think that physicians are growingly increasingly aware of it. It takes time for information to trickle out to the entire medical community.

**Victoria Ruff
(Moderator)**

22. Question from Claudia: If there are no hallucinations, is it still LBD?

Dr. Gomperts

The core criteria for a clinical diagnosis of probably DLB are (a) dementia, accompanied by (b) at least 2/3 of (1) spontaneous features of parkinsonism, (2) recurrent visual hallucinations, and (3) cognitive fluctuations with marked variation in level of alertness or attention. So, as you can see, you don’t actually need to have hallucinations to have “probable DLB”.

In addition, (for your information) while you need (a) and (b) for a clinical diagnosis of probable LBD, you can call it “possible” DLB with only 1/3 of those (b) criteria. And you can bump from “possible” to “probable” if the patient has (i) neuroleptic sensitivity, (ii) REM sleep behavioral disorder, or (iii) evidence for loss of dopamine transporter signal on a nuclear medicine scan of the dopamine transporter. With these clinical criteria, we presently do a moderately good (but not very good) job in identifying people whose brains (at autopsy) show the characteristic changes that define LBD. That said, we are trying to come up with better diagnostic techniques.

At present, the diagnosis can only be made certain by looking at the brain at autopsy.

Another thing to keep in mind is that in DLB, cognitive problems occur before or concomitant with parkinsonism. In contrast, in Parkinson Disease dementia, Parkinson Disease comes first, and patients only develop cognitive problems subsequently.

(We currently arbitrarily require a 1year interval from PD to onset of dementia to call it PDD; if less than that, we call it DLB.) Clinicians are currently studying how DLB and PDD are related.

**Victoria Ruff
(Moderator)**

23. Question from Bobbi: What is being done to publicize LBD?

Dr. Gomperts

The LBD Association, which is hosting this chat forum, is a major resource for publicizing LBD. You all have its contact information. The Alzheimer's Disease Association is another. Parkinson disease groups, such as the Parkinson Disease Foundation, are another resource, although they tend to focus primarily on the motor problems of PD.

This condition is gaining attention among doctors, especially those who see PD and dementia patients. As a result, within the medical community, LBD is increasingly studied, and scientific progress often heralds increased research funding and therefore public awareness.

**Victoria Ruff
(Moderator)**

24. Question from Claudia: Do the symptoms progress gradually or rapidly?

Dr. Gomperts

Progression of disease varies greatly across different people. Acetylcholine esterase inhibitors like Aricept, Exelon, and Razadyne (and possibly the agent memantine) can help many DLB patients' symptoms (to varying degree), even though they do not treat the underlying disease.

From onset of dementia, on average, patients tend to live less than a decade, but there is a large amount of variability across patients, so that is a very rough guide.

**Victoria Ruff
(Moderator)**

25. Question from Sandy: I would like to know what differences appear between AD and LBD patients' actions or reactions or abilities. Do LBD patients bounce from good days to bad days more often sometimes changing hour to hour?

Dr. Gomperts

The cognitive profiles of early AD and LBD vary, but as these diseases progress, they can appear to converge. Loss of short-term memory is the key signature of AD. There may (or may not) be trouble with word finding or name retrieval. There may (or may not) be temporal disorientation (time, date) and/or spatial disorientation (e.g. newly getting lost when driving).

With time, judgment and planning can get affected as well. In severe, late cases of AD, there may be hallucinations or delusions. There are no motor changes of parkinsonism.

Some patients with LBD present similarly to AD in terms of their cognitive profile. Others have more initial trouble with attention and judgment and planning (so called executive function). There may also be a marked problem with visuospatial skill (more than AD for a given level of cognitive decline). In addition, some patients with LBD (but not all) have "cognitive fluctuations".

Dr. Gomperts

This term refers to changes in level of alertness that can occur over several timescales, day-to-day, hour-to-hour, and sometimes even minute-to-minute. What you describe is a typical example of these fluctuations. Cognitive fluctuations are not typically seen in AD (though they can occur with metabolic or infectious disturbances, like a urinary tract infection).

In addition, patients with LBD frequently develop hallucinations or delusions early on in the course of disease, along with parkinsonism.

Victoria Ruff (Moderator) Thank you Dr. Gomperts - before the floor opens... Angela Taylor (President, LBDA Board of Directors) has something to say...

Angela Taylor On behalf of the LBD Association, I'd like to thank Victoria Ruff for the initiative to launch this event. She deserves the lion's share of the credit for asking LBDA to host the event.

I'd also like to thank Dr. Gomperts for helping us with this pilot chat event. Our deepest appreciation for your time and knowledge!

Dr. Gomperts Thank you for the opportunity to speak with you.

Hynda What do you think of the medicine Detrol to control frequency of urination?

Dr. Gomperts As I wrote above, so called anticholinergic agents that are used for urinary urgency can cause cognitive problems.

Detrol is one of these agents. If possible, non-anticholinergic agents would be preferable from my perspective, to remove any cognitive side effects.

colourful My husband age 71 was diagnosed at UBC in Vancouver in 2003 he has been on Aricept since. He had a question about visual disturbance, loss of ability to read which have become more troublesome. He has trouble recognizing a common face across a room, getting lost in his room of off days.

Dr. Gomperts If colourful could please clarify her question, I would be happy to address it. I do not understand what you are asking.

colourful How should visual testing be done for person with LBD? Are there any special considerations?

Dr. Gomperts The major issue is how do you address a subjective complaint in a person with dementia.

It isn't always easy. His neurologist can assess him for a brain basis for his visual problems.

If he is unable to tolerate an ophthalmologic exam, and cannot articulate his problems, then it may be difficult.

chet Can too much of a med like Seroquel cause patient to regress and loose a handle on reality?

Dr. Gomperts Too much Seroquel can certainly cause sleepiness and asthenia. I would not expect it to cause confusion per se, if titrated up gradually and systematically as needed.

Elizabeth Are there any antibiotics that are on the 'bad list'?

Dr. Gomperts I do not currently recall any antibiotics that are particularly notorious in DLB.

claudia My husband's neurologist has mentioned Donepezil as a possibility to mitigate some of the non-cognitive issues. Are you familiar with this drug?

Dr. Gomperts Donepezil is also known as Aricept. I discussed it above for treatment of the cognitive problems that arise in LBD.

Studies have shown that Aricept and Exelon can both help.

Anita How do you feel about computerized bio-feedback units? Would it be more of a hindrance than useful?

gragrah My husband was on Seroquel but was changed to Risperdal when the 325mg of Seroquel seemed not be helping. I wonder if the Seroquel could or should be started again at a higher dose and the Risperdal discontinued due to side effects?

marcia Are you familiar with the med Abilify? What do you think of it for agitation/aggression in LBD patients?

griff How does one access clinical trials?

admin griff (and others): you can find clinical trial information here: <http://www.lewybodydementia.org/trials.php>

EricSEA Of the three currently marketed agents that have been studied in the NET-PD trials (minocycline, 2400 mg/day CoQ-10, creatine 5 g bid), are there any that you would feel were too risky to use off-label while more definitive trials for efficacy are conducted?

Charley Does heat intolerance occur with LBD?

Victoria Ruff (Moderator) No more questions please...

Victoria Ruff (Moderator) Would you mind my emailing you the rest?

Dr. Gomperts Not at all.

Victoria Ruff (Moderator) Wonderful! THANK YOU Dr. Gomperts -- very much appreciated!

Dr. Gomperts Dr. Gomperts quit (leaves the chat room)

Victoria Ruff (Moderator) Everybody -- I'll grab those questions not posed and email Dr. Gomperts & then email you all the answers...

Questions that were emailed to Dr. Gomperts for further answers:

- Anita** How do you feel about computerized bio-feedback units? Would it be more of a hindrance than useful?
- Dr. Gomperts** Bio-feedback tools vary widely. They can be used for many purposes, including cognitive therapy and improving motor function. Some may be helpful in the right setting, but they are largely still experimental tools and are not yet well-validated. Your physician may be able to guide you in the utility of one in your specific circumstances. A patient has to be able to understand and complete the task at hand, so computer program associated therapy may be more helpful earlier in the course of disease.
- gragrah** My husband was on Seroquel but was changed to Risperdal when the 325mg of Seroquel seemed not be helping. I wonder if the Seroquel could or should be started again at a higher dose and the Risperdal discontinued due to side effects?
- Dr. Gomperts** Without evaluating your loved one, I do not have sufficient information to make clinical recommendations. Speaking generally, Risperdal is more likely than Seroquel to cause significant side effects in patients with LBD.
- marcia** Are you familiar with the med Abilify? What do you think of it for agitation/aggression in LBD patients?
- Dr. Gomperts** Because Abilify is a relatively new neuroleptic (antipsychotic agent), we do not have extensive experience with it yet. Its potential to worsen parkinsonism in patients with LBD would lead me to use it only with extreme caution.
- griff** How does one access clinical trials?
- Dr. Gomperts** The LBDA website has a very useful list of clinical trials and clinical trial resources for you to explore (under Resources), including those recently approved by the FDA. Other online resources exist as well. Your doctor may also know about or be involved in relevant clinical trials. Patient information resources at academic hospitals in your metropolitan area are an additional good place to ask.
- EricSEA** Of the three currently marketed agents that have been studied in the NET-PD trials (minocycline, 2400 mg/day CoQ-10, creatine 5 g bid), are there any that you would feel were too risky to use off-label while more definitive trials for efficacy are conducted?
- Dr. Gomperts** Minocycline has known drug interactions and has been associated with a variety of adverse reactions. It should be used cautiously, if at all, under the guidance of a physician. Creatine and CoQ-10 appear to be less likely to cause problems, if used in appropriate doses. All medications should be used under the guidance of a physician.
- Charley** Does heat intolerance occur with LBD?
- Dr. Gomperts** I am not sure that I understand what you mean by heat intolerance. Heat intolerance, per se, is not a classic symptom of LBD. Patients with LBD, however, can be physically and cognitively frail, and thereby more susceptible to extremes of temperature.

- EricSEA** Could you comment on your use of psychostimulants in your clinical practice?
- Dr. Gomperts** I use psychostimulants in a subset of my patients with neurological diseases, to increase arousal. When prescribed, they need to be used cautiously and monitored closely by a physician.
- NH Bob** How can we find Doctor(s) that have an interest in treating patients with LBD? Our challenge is to find a Doctor(s) who can suggest different medications to alleviate the classic LBD symptoms. (PS from Moderator, Victoria Ruff -- Dr. Gomperts, NH Bob is in NH and his mother is in Boston -- are you accepting new patients? or someone on your LBD team accepting new patients? Thanks in advance)
- Dr. Gomperts** General neurologists (and General Practitioners and Internists) have the option to refer to Dementia and Movement specialists to get additional input on LBD management. A patient can always request a referral. Dementia doctors tend to focus on the cognitive problems, and movement doctors on the motor complaints, but that is not always the rule. For additional input on LBD management in the New England area, one option (of several) would be referral to the Massachusetts General Hospital Movement Disorder Unit and Memory Disorder Unit. I am taking new patients in the Movement Unit and would be happy to see your family member in clinic. If he is interested, you or he can call (617) 726-5532 to make an appointment.