



The Virtual Assessment in Lewy Body Dementia: Pandemic and Beyond Webinar Series

Webinar #3: Impact of COVID-19 in those with LBD

Frequently Asked Questions (FAQs) – Response

1. *Is the administration of tools like the MDS-UPDRS necessary for the diagnosis of Parkinson’s disease or Lewy body diseases?*

Answer: The presence of parkinsonism is one of the core clinical features of the DLB criteria (McKeith et al., 2017) and includes bradykinesia, rest tremor, or rigidity. These criteria do not specify particular measurement tools or rating scales for identifying or rating motor parkinsonism. However, at present, one must be able to recognize the presence of parkinsonian motor symptoms on clinical exam in order to incorporate this as a feature that is present or absent in the diagnostic criteria. The MDS-UPDRS by Goetz et al., 2008 (and previously the UPDRS) includes the motor examination (part 3) in which bradykinesia, tremor, rigidity, gait, posture, and postural instability are evaluated and is frequently used to evaluate motor features of parkinsonism.

2. *Is a DATSCAN needed to make a diagnosis of Lewy body diseases?*

Answer: Dopaminergic imaging scan such as the DaTSCAN can be very helpful for making a diagnosis of Lewy body disease (Parkinson’s, dementia with Lewy bodies/DLB etc.) and is now listed as an indicative biomarker in the 2017 McKeith consensus criteria for DLB. However, to make a diagnosis of DLB – you don’t always need a DaTSCAN. One can do this on clinical assessment alone or indeed by using other imaging approaches such as an MIBG scan. Where DaTSCAN is helpful is in cases where you suspect DLB but are not entirely certain. In these circumstances a DaTSCAN can potentially help you rule in or rule out DLB depending on the clinical context.

3. *How would you recommend those with LBD stay cognitively stimulated while following recommendations for social distancing during the COVID19 pandemic?*

Answer: There is, unfortunately, no clear evidence base to provide specific recommendations particularly in LBD. However, based on experience and anecdotal observation as well as pulling in approaches used in other conditions there are a number of approaches that could be considered that might help:

- Build an expectation of contributing to everyday tasks. For example: doing the washing up, setting the table (even if it is messy and has to be subtly redone), making a shopping list (pictures to tick if necessary), making up pot plants sat at kitchen table if not safe to garden alone etc.
- Other things include coloring like simple pictures or sticker books on a topic that interests them. People have also found that doing jigsaws made for adults (so not childish picture) but with few pieces is

enjoyable (there are plenty of stockists online). Other activities could include dominoes with pictures (not numbers) and bingo matching cards that can be done alone or together.

- If funds allow there are very simple tablets that can be rented from online suppliers. They can be rented by the month to see how people find them and have hardly any icons with all of these in large pictures. Activities on the tablets can be done remotely but together with others.
- Regarding phone calls – we would recommend focusing on particular topics without putting the person living with LBD on the spot i.e. say you are going to give a call later that day because you would like to chat about e.g. holidays, pets, previous cars (an example of a reminiscence activity).
- Others benefit from the use of reminiscence cards to stimulate conversation. This can be done by printing off old pictures (or finding similar photos on the internet). Ask family members to call for a piece of advice or information depending on persons previous job/hobbies as often recall for this can be quite good.
- Some specific occupational activity ideas which we have used and may also help include:
 - Make a playlist of a few songs and ask about what they remember from when the song was first popular.
 - Make up a bag of textured material, wool, ribbon, buttons etc. for conversations about previous craft activists and maybe start new ones, threading, sorting etc.
 - Find a few scented things and see which are preferred & anything they remind the person of.
 - Watch highlights of favorite sporting events i.e. YouTube clips and talk about why they were so great, where the person first watched them etc.
 - Have a few ice-cream flavors and do a tasting (can be done alone make a simple tick box chart for which they prefer; other family members can do and then talk about over the phone about what flavors they preferred)

These activities are about attempting to engage all the senses at different times which may help with wellbeing and quality of life.

- Some have found that daily short walks outside, if safe, or in the garden, or sitting at the front door watching people and traffic pass by, helped with wellbeing.
- Consider involving friends / acquaintances from previous activities who may have suggestions of ways to modify their own activity rather than the carer having to think of how to do this.

4. *What might be the explanation for the observation in the survey study that hallucinations increased in those with LBD during the COVID19 pandemic?*

Answer: It is hard to know exactly the reason for this, but we can speculate that there are number of potential contributors. Firstly, the pandemic has increased the likelihood of people with LBD being more socially isolated and we know that lack of contact with others, being under a degree of stress and having a lack of stimulation can exacerbate hallucinations. Secondly, as was evident in the survey a lot of other symptoms worsened so the increase in hallucinations may simply be a consequence of this. Reduced contact with healthcare providers and potentially key caregivers may have meant that many symptoms worsened and become more severe due to lack of timely intervention(s).