

## **Robin's Wish: discussion with the film's Director Tylor Norwood**

On 8<sup>th</sup> January 2021 we held an online event to discuss the film Robin's Wish.

The panel was:

Jacqui Cannon, Chief Executive of the Lewy Body Society

Tylor Norwood, Director of Robin's Wish

Rachel Thompson, Consultant Admiral Nurse, The Lewy Body Society

Professor John-Paul Taylor, Professor of Translational Dementia Research, Newcastle University

Due to time constraints we weren't able to answer all the questions asked by attendees. We have therefore collated them and our clinical experts have provided additional answers. We haven't been able to answer specific questions about Robin Williams and his experience.

We have also included some links for further information and support.

## **Symptoms and diagnosis**

**It seems that in the US it isn't as common as in the UK to have a DAT scan, more likely to diagnose after someone has passed away. Is this correct?**

*Our experience is in the UK but further information relevant to the USA can be found at <https://www.lbda.org/>.*

*Lewy bodies can show up on certain scans known as a SPECT, PET or DAT scans. These scans measure the level of dopamine in the brain which are usually low in Lewy body dementia. It involves having an injection of a special (radioactive) substance, which helps show how much dopamine is being transported in the brain. Scans commonly used in diagnosing dementia i.e. MRI or CT scans may show some damage but it may not be clear if this was caused by Lewy bodies or another type of dementia.*

**Where should people go for a diagnosis? It seems to me that psychiatrists need training in this. My late wife saw two but neither picked up on this.**

*The GP should be your starting point. People can be given a 'possible' or 'probable' diagnosis of LBD following a thorough assessment of their symptoms and history by specialist services. This should include:*

- *Cognitive assessment –this should focus on changes in visual- perception (difficulty with interpreting visual images or bumping into things) and fluctuations in alertness ( sudden changes in ability), the ability to carry out activities such as planning & organising tasks as well as the usual cognitive questions about changes in memory (this may be less pronounced in earlier stages)*
- *Neuropsychiatric symptoms such as visual hallucinations/ delusions, apathy/depression. Recurring visual hallucinations – (often animals or people) are one of the core symptoms of LBD and may be quite threatening or scary, although not always. These may be described as a 'sense of presence' – feeling that someone is there OR be quite vivid. People may also experience delusions which can be linked to the hallucinations or experience misidentification syndrome known as Capgras where someone familiar may seem to be an imposter.*
- *Sleep disturbance – REM Sleep behaviour disorder is another of the key features in which people are restless and can experience intense dreams or nightmares. This symptom can occur years before other symptoms occur and a diagnosis is made.*
- *Motor symptoms such as slowed movement, difficulty walking, shuffling or appearing rigid – 'freezing' (as in Parkinson's disease), tremors - usually in the hands, particularly during movement and problems with balance/ being prone to falls.*

*The Diamond Lewy project is developing ways to help improve doctors' awareness of LBD as well as how they can better assess for it:*

<https://research.ncl.ac.uk/diamondlewy/assessmenttoolkits/>

### **Is there any research into better diagnostic tools re the cortex damage that would show the disease?**

*Clinically we have found there are certain questions and approaches that might help with making an diagnosis (used in now in the Diamond-Lewy programme*

<https://research.ncl.ac.uk/diamondlewy/assessmenttoolkits/>

*A lot of our tests such as DAT scans can only indirectly tell us there is changes that occur in Lewy body disease. Scientists are now working on new brain imaging techniques which directly measure the pathological protein. In addition, there is some exciting work emerging that we might be able to make the diagnosis from taking a sample of the fluid from the spine or indeed a simple blood test. So things are advancing rapidly.*

### **Need to know what is happening that Dopamine is so badly affected in the Substantia Nigra and other areas of the Cortex. And why aspects of other conditions such as parkinsonism and AD also jumps on board, is it an auto immune thing?**

*This is an interesting point. We think a lot of the neurotransmitter systems are deeply affected: dopamine, acetylcholine, noradrenaline, serotonin etc. There is also a great deal of interest now in whether the immune system plays a role in triggering neuroinflammation which contributes to the brain changes.*

## **Can tremors turn into Parkinson? What is the difference?**

*Tremors may be an indicator of Parkinson's but there may be other causes, such as changes in medication, anxiety and/or other conditions. Further tests and monitoring would be required to establish if this was related to Parkinson's.*

*Other motor symptoms that are indicative of Parkinson's include slowed movement, difficulty walking, shuffling or appearing rigid – 'freezing' (as in Parkinson's disease), tremors - usually in the hands, particularly during movement and problems with balance/ being prone to falls.*

*Both Parkinson's disease and Lewy body dementia are caused by Lewy bodies which are abnormal clumps of protein that gather inside brain cells and impair functioning. Lewy bodies are present in people who have Parkinson's disease, usually in the areas of the brain responsible for movement*

## **Is suicide common in patients with LBD?**

*People with LBD can experience symptoms of anxiety and depression which may be linked to an increased level of insight and awareness of their condition. People with severe depression can be at increased risk of suicide and it is important to seek professional help if someone has suicidal thoughts.*

*Responses to symptoms vary from person to person and are influenced by the nature of other symptoms, usual coping styles, awareness/ insight and the stage of the condition.*

*Research is ongoing at the moment to try and understand suicide rates in LBD as this question is something which is commonly raised by the LBD community*

## **Awareness among medical professionals**

### **Has the NHS got time for LBD? It is very time consuming for professionals**

*It can be more challenging – that is why the Diamond Lewy project developed a brief assessment toolkit to help doctors <https://research.ncl.ac.uk/diamondlewy/assessmenttoolkits/> Generally secondary care doctors should have enough time to see and assess people.*

*It is hard for GPs who need to know something about everything and therefore can't be experts. Key is that they can pick up on some red flags so they can refer people on to get a more detailed assessment.*

**Should there be a greater push to increase knowledge not just of neurologists but psychologists as there seem a lack of knowledge or desire to look for an alternative cause - the family is not really listened to.**

*This is a challenge and improving the awareness of LBD as the most common dementia you have never heard of is vital. The film is an important flag bearer in this regard.*

## **Treatment**

### **To improve memory -what kind of cognitive stimulation examples can you suggest?**

*There is no one specific thing. I would advocate that people do what they enjoy i.e. crosswords, puzzles, quizzes rather than worry about trying to do things that they don't like.*

*In addition, social connection is vital – even if this just has to be virtual at the moment. And finally – getting out (helping with melatonin levels) and exercise seem really important.*

*Finally healthy balanced diet and making sure that getting enough Vitamin D is also something I advise. Vitamin D is not specific to LBD – rather important to have strong bones and good immune system.*

### **Why can People with Lewy bodies not be admitted to a hospice for end of life care?**

*Hospice and palliative care should be freely available for people with Lewy body dementia at the end of life, although sadly support is not always offered as well as it should be. Although previously, people with dementia were often excluded from palliative/ hospice care – this changed approximately 8- 9 years ago and the expectation is that support should be made available.*

*Sadly some services may say they do not have the expertise to support people with dementia but this should be questioned and people should not be excluded on the basis of diagnosis alone. There are some good examples of hospices offering specialist dementia support.*

*Further information can be found at Hospice UK – see: <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/hospice-enabled-dementia-care>*

### **I work in theatre with people with dementia and I'm interested in how well Robin was able to cope with the changes he experienced and how his skills in improvisation may have supported this. Do we have much evidence for creative interventions to support people with Lewy Body dementia?**

*Not specifically – we looked at review on this. Generally tailored non-pharmacological interventions can have a role but more research is needed.*

## **Research**

### **Would it be helpful to donate his brain for medical science and how would we go about it?**

It would be about contacting your nearest brain bank - <https://mrc.ukri.org/research/facilities-and-resources-for-researchers/brain-banks/donating-brain-and-spinal-cord-tissue/>

The following which is a joint venture between the Alzheimer's Society and Alzheimer's Research UK to support brain donation may also be helpful: <https://www.brainsfordementiaresearch.org.uk/>

### **Campaigning/awareness raising**

**How do we globally build on this amazing and crucial "new" awareness and drive the training and research needed to help sufferers with real practical solutions? What next? We can't just now heighten awareness and then allow it to dissipate.**

*You are absolutely right. The film will make a big difference in raising awareness of Lewy body dementia. The decision by Robin's family, friends and colleagues to speak out means that there are now lots of media articles that refer to Lewy body dementia that simply didn't exist before, and many more journalists and policymakers will have heard of the disease. The Lewy Body Society will certainly try to build on this momentum through our fundraising and awareness raising activities, working in partnerships with the global research community and other charities, to ensure Robin's Wish has a lasting legacy of change.*

**Can schools not share Robin Wish in PSChE and start raising awareness from school age?**

*This is a good idea and we will think about how to take it forward. There are some resources about dementia aimed at children, but none specific to Lewy body dementia that we are aware of.*

### **Sources of information**

If you would like further information about symptoms, diagnosis and treatment, this is all covered in our book '**A Guide to Lewy body dementia**'. You can find it on our website <https://www.lewybody.org/resources/> or email [info@lewybody.org](mailto:info@lewybody.org) and we can post you a copy (in the UK) or send you the PDF.

The **Admiral Nurse Dementia Helpline** is available 9am-9pm Monday to Friday and 9am-5pm on the weekend. Call free on 0800 888 6678 or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org).

Visit <https://www.dementiauk.org> for further information and resources.

To find out more about taking part in research, visit **Join Dementia Research** here: <https://www.joindementiaresearch.nihr.ac.uk/>.

There are very few locally based support groups which are specific to Lewy body dementia and you would need to enquire with local dementia services/ providers about what is available in your area.

The following national services offer some online support groups:

**Rare Dementia Support (RDS)** Support a Lewy body support group which runs twice a year see: <https://www.raredementiasupport.org/meetings/>

**DEEP (Dementia Engagement and Empowerment Project)** DEEP consists of around 100 groups of people with dementia and is a UK wide network – it connects groups to each other to share learning and skills and to increase confidence. See here to find out about different groups available: <https://www.dementiavoices.org.uk/deep-groups/>

**tide - together in dementia everyday** –This is a UK wide involvement network of carers, former carers and health and care professionals who are working together to build a better future for carers of people living with dementia. It also offers some online support and events for family carers of people with dementia – see: <https://www.tide.uk.net/tide-events/>

**Lewy buddies** - If anyone in the UK would appreciate peer support, please contact [lewybuddiesUK@gmail.com](mailto:lewybuddiesUK@gmail.com) - there are Lewy Buddies from Edinburgh to Penzance, and places in between :)

If you need information about supporting people living with dementia to remain engaged in activity and connected to loved ones contact **NAPA** visit the website [www.Napa-activities.co.uk](http://www.Napa-activities.co.uk) or call the NAPA helpline [http://napa-activities.co.uk/wp-content/uploads/2020/08/NA\\_1013\\_helpline-logo-small.png](http://napa-activities.co.uk/wp-content/uploads/2020/08/NA_1013_helpline-logo-small.png)

**Dementia Together Suffolk**, Sue Ryder, 08081688 000 <http://www.dementia-together.com/>