



Another Presence

A film about dementia, hallucinations and altered perceptions



Produced, Directed and Animated by
Simon Ball

In collaboration with Dr Rimona Weil (University College London)
and Rare Dementia Support

Funded by Alzheimer's Research UK - Inspire Fund



www.anotherpresencefilm.com

 @DLB_film  @DLBfilm  dlbfilm



Short Synopsis (26 words)

Told through the testimonies of people living with dementia with Lewy bodies, Another Presence explores the unique and often surreal experiences of this little understood condition.

Long Synopsis (79 words)

Another Presence recounts the unique and often curious experiences of people living with dementia with Lewy bodies (DLB), the third most common form of dementia in the UK. A multi-sensory condition that can cause dream-like symptoms, it's a condition like no other. Told through the testimonies of those living with DLB, the film explores the surreal and lesser known effects of dementia, compelling us to question how our brains function and to what extent we can trust our senses.

Technical Information

Film Title Another Presence	Screening Format Colour 16:9 25fps QT Prores / DCP
Project Type Animation, Documentary, Short	Country of Origin United Kingdom
Runtime (inc. credits) 12 minutes 02 seconds	Language English
Completion Date 1st March 2022	Subtitles / Captions English

For further information, festivals & screenings, please contact:
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Another Presence - Backstory

The origins of Another Presence really ~~began during the~~ production of my first documentary project, 'Do I See What You see?'. That film was about people with a rare form of visual Alzheimer's known as Posterior Cortical Atrophy or PCA. Throughout the production, I worked closely with the organisation Rare Dementia Support (RDS) to learn about the condition and meet potential participants.

It was through this connection that I was introduced to Dr Rimona Weil, a clinician and neuroscientist working with people with dementia with Lewy bodies (DLB). Alongside her clinical work, Dr Weil organises the RDS support group for people living with DLB. As a visual artist, DLB was particularly interesting due to the wide array of visual symptoms experienced by those with the condition. In particular, people's accounts of visual hallucinations were like nothing I had encountered before and, aside from being unique in almost every sense, were another example of dementia symptoms echoing the language of animation. Together, myself and Rimona were awarded funding by Alzheimer's Research UK's (ARUK) Inspire Fund to develop and produce an animated work exploring DLB and visual hallucinations.

Through the Rare Dementia Support events and alongside ARUK and the Lewy Body Society, I was able to meet and connect with a wide network of people living with DLB, many of whom not only had experiences of visual hallucinations, but had a remarkable level of insight into their own experiences. My first interview, with a daughter and her mother who lived with DLB, was one of the most fascinating conversations that I've ever had. It wasn't simply the range of symptoms that they had experienced, but the way these symptoms blended into and fluctuated with one another that, to hear them, left you unsure as to what was real and what was not. Hallucinations, dreams and delusions, as well as problems with cognitive function, such as remembering sequences in time, made for a very surreal conversation. And yet throughout all of this, the mother remained remarkably lucid, giving objective insight and often making jokes about the strangeness of the whole story.

There followed six more interviews, each unique in terms of symptoms and character. Bringing these stories together into a short narrative was a huge challenge. Although the intention was always to focus the film on the visual symptoms of DLB, the condition is multi-system, encompassing physical and movement difficulties similar to those seen in Parkinson's disease, as well as a wide array of cognitive symptoms that affect thinking, attention and memory. In addition to this, the variety of visual hallucinations that people recounted were not only broad, but also very detailed and often part of wider stories and events, both real and imagined.

The events organised by RDS allowed me to share my progress with people living with DLB. At different stages of the project, I was able to present audio, artwork and test animations to people with first hand experience of the condition. This meant that people with lived experience of DLB fed-back directly on the tone of the film and influenced the decisions I made throughout.

There were so many angles from which to approach the subject of DLB that I spent a lot of time experimenting with different styles and techniques in order to develop a visual language and narrative approach that reflected both the variety of symptoms as well as the individual characters I spoke with. Right up until the final few months of production the structure of the film felt changeable. My aim was to allow the most powerful anecdotes as much room to breathe as possible, allowing viewers to share in the depth and detail of people's Hallucinations. At the same time, I've tried to keep the different scenes as varied as possible, to hint at the wide array symptoms that DLB can cause as well as their fluctuating nature.

Featuring Testimonies From...



Melanie Jarman & her mother Roselyn Watson

My mother, a bright, witty, vivacious woman, called me one day because there were children in her house who wouldn't leave; when I got there I saw no one. While there had been significant signs that something was wrong before that, it was a turning point as it was the first time mum acknowledged she didn't understand what was happening to her. Those children became both a blessing and curse, and I learned quickly to acknowledge them with her.

Ros was officially diagnosed with LBD in 2019, which came as a relief in many ways. The 'children' lived with her until she moved to a care home; she looked after them, and had to be persuaded they would be OK if she went out. When I was clearing her house later, I found plates of food tucked away for them so they wouldn't go hungry.

Our shared love of knitting, texting (!) and going to the pub, was thwarted early on and caused mum great frustration, especially as she couldn't understand why. I am learning how to be there for her in different ways now, but I find it impossible to articulate just how much I miss her.



Des O'Sullivan and Valli Yanni

Des is an accomplished Educational Publishing Project Manager who was diagnosed with DLB 5 years ago, at the age of 60. Valli is a consultant in international development. Des (Irish) and Valli (Egyptian) are based in Oxford and have been married for almost 27 years.

The diagnosis of DLB has forced Des to decide on an early retirement, and Valli to reduce her workload to accompany Des in their shared journey of the ups and downs of LBD. They both have a positive attitude to living well with dementia. They are very open, vocal and articulate about sharing their experience. Their little dog Milo, as well as yoga have kept Des very physically active. Music, films and audio books have kept Des mentally and intellectually stimulated. The support of family and friends and regular meetings with other people living with dementia have sustained Des' social engagement. Des and Valli are keen advocates for a dementia-friendly society through public speaking and research and media involvement. Living a New Life is a short film about Des and Valli's experience with DLB:

<https://www.youtube.com/watch?v=MFvSXI9t9i8&feature=youtu.be>

Featuring Testimonies From...



Esther Boyd, who's husband Howard had DLB

We had looked forward to an active retirement, but Howard became frustrated as he felt inefficient and unfit. He had always been a keen cyclist – he rode a tricycle to Egypt with two friends when he was 19 and got a cycling 'half blue' at Cambridge University. His varied career ended as a transport engineer, focussing on projects that improved safety for cyclists.

Howard welcomed his diagnosis of DLB (aged 67) as it explained his difficulties. Together we worked hard to slow down the progression of the disorder – and even reversed some symptoms, for about two years, unblocking neural pathways by rapid cycling on a tandem turbo trainer we had set in the garage.

We wanted to meet other people who were affected by LBD. It took 5 years to overcome the obstacle of Data Protection. The peer support that followed lived up to our expectations. After Howard's death I set up a group, called Lewy Buddies UK. Buddies support each other by sharing experiences, providing a listening ear. The group is growing steadily across the country.

Gill and Jeff Keighley and their daughter Laura

We met over 40 years ago whilst Jeff was studying for his second Masters degree at Cranfield. As he managed increasingly larger engineering/manufacturing companies, we moved around the country a lot. He was diagnosed in February 2019 after over a year of trying to convince the doctors that he had dementia. It was a relief to get a diagnosis, but support has been patchy and largely only found through Gill's research. Our lives have changed hugely as the daily fluctuations in cognition, physical deterioration and levels of hallucination lead to difficulty in making plans for day to day living, with Gill having to take early retirement to care full time for Jeff. The Covid 19 restrictions have certainly had quite an impact on the effect of this disease.

And...

George and Anita Varey
David Slater and Fiona Geddes
Philip and Helen Robins

About dementia with Lewy bodies

Dementia with Lewy bodies is closely related to Parkinson's disease, but they are different conditions. The build-up of Lewy bodies is also found in Parkinson's, and leads to symptoms like movement problems and tremors. Dementia with Lewy bodies and Parkinson's disease dementia can affect people in very similar ways. If memory problems and dementia symptoms appear before or at the same time as movement problems and symptoms, then a diagnosis of DLB is likely to be given.

About 10-15% of all people with dementia have DLB. This means that approximately 100,000 people in the UK have DLB. It affects both men and women, usually older than 65 years.

What are Lewy bodies?

Lewy bodies are protein deposits that can be found in the brain of people with DLB and with Parkinson's disease. Scientists still don't know exactly how they cause dementia but they may lead to loss of connections between brain cells. The symptoms that people with DLB will experience depend on where the Lewy bodies are found. When Lewy bodies are mostly found in the deeper parts of the brain, they lead to problems with movements and Parkinson's disease. When they are found in the outer parts of the brain they tend to lead to problems with thinking and DLB.

Common symptoms of DLB:

DLB affects different people in different ways. It often causes problems with concentrating and staying alert. Although day to day memory can also be affected, it is less of a problem than in people with Alzheimer's disease. People with DLB and their families often notice that thinking and memory problems vary from day to day or even hour to hour. DLB can also cause visual hallucinations, such as seeing animals or people that are not really there. In many people, these are not troublesome, and would only need treatment if they become distressing. People with DLB may notice that their movements are slower or stiff. Some people have problems with falling. Other symptoms can include problems with bladder or bowel function, and sleep troubles. DLB is a progressive condition and symptoms generally become worse over time. The rate at which symptoms become worse varies from person to person.

Produced in collaboration with



Rare Dementia Support (RDS) aims to empower, guide and inform people living with a rare dementia diagnosis and those who care about them. Combining social, emotional and practical support with research and training about rare dementias, we are working to increase awareness about these conditions so that everyone affected by rare dementias feels better supported in their communities.

RDS run support groups that bring people together to share their experiences and provide a Direct Support Team, who are available by email and telephone. They endeavour to listen to and discuss situations with empathy, respect and professionalism.

The diagnosis of a rare dementia brings with it a set of unique and complex challenges which can include difficulties with vision, language, movement and behaviour. There is a widespread lack of understanding and a shortage of dedicated resources to support people affected by rare dementias.

RDS' vision is for everyone affected by, or at risk of a rare dementia, to have access to information, tailored support and guidance, and contact with others affected by similar conditions, in a space of mutual respect, community and understanding.

Rare Dementia Support (RDS) is a world-leading, UK-based service provided by the UCL Dementia Research Centre (DRC) and partners and funded by The National Brain Appeal.

<https://www.raredementiasupport.org/lewy-body-dementia/>



Alzheimer's Research UK Inspire Fund – Public Engagement Grant

Unless we act now, one in three people born today will develop dementia in their lifetime. But there is hope. Because dementia is caused by physical diseases, and diseases can be cured.

At Alzheimer's Research UK, our vision is a world where people are free from the fear, harm and heartbreak of dementia.

Alzheimer's Research UK is the UK's leading dementia research charity. We are dedicated to making breakthroughs in diagnosis, prevention, treatment and cure, for all types of dementia.

Backed by our passionate scientists and supporters, we fund and deliver pioneering research. We challenge the way people think about dementia and bring together the people and organisations who can speed up progress.

We believe that medical research can and will deliver life-changing preventions, treatments and one day, a cure for dementia. Alzheimer's Research UK exists to make this happen. For as long as there are people and families affected by dementia, our work goes on.

Inspire Fund

The Inspire Fund is part of our work to tackle misconceptions around dementia and promote the importance of dementia research. Traditional methods of disseminating information and building knowledge do not always reach those who would benefit most. We created the Inspire Fund to spark innovative engagement projects, supporting grassroots activity and utilising creative methods. Through the grants scheme we have supported partnerships between researchers, communities and creatives, to build understanding of what it means to be affected by dementia, and the hope that lies in research.

www.alzheimersresearchuk.org

Credits

Produced, Directed and Animated by
Simon Ball

Research Advisor
Dr Rimona Weil

Special thanks to
Nikki Zimmermann, Prof. Sebastian Crutch,
Alicia Willoughby, Emily Brotherhood, Dr Angeliki Zarkali,
and the team and members at Rare Dementia Support

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Thanks to
Katy Bray & Rachel Allen at Alzheimer's Research UK
Kathleen Rode, Dominic Power, Lorenza Manfredi, Jacqueline Cannon,
Kate Groucutt, Nick Street, Jane Langton, The Lewy Body Society, Katie Ball,
Victoria Muscat, Ben Pace, Christian Stoss, Officina, Miet Studio, Open City
Documentary Festival

Supported by



Production Bios



Simon Ball - Producer, Director, Animator

Simon Ball is an award winning film-maker and animator working across abstraction, documentary and commercial projects. He has over ten years experience as a freelance animator and motion designer, spanning broadcast, film and commercial projects. His abstract works, in collaboration with Zai Tang, have screened and exhibited internationally. Simon's most recent documentary 'Do I See What You See?', about people living with a rare form of Dementia' was awarded 'Best Commissioned Film' at the Manchester animation festival and continues to be screened widely in scientific communities.

www.simon-ball.com



Dr Rimona Weil - Research Advisor

Dr Rimona Weil is a Consultant Neurologist specialising in Dementia with Lewy Bodies and Parkinson's disease dementia at the National Hospital for Neurology & Neurosurgery, University College London Hospital. Alongside this she leads a Wellcome-funded research programme at the UCL Dementia Research Centre aiming to understand how dementia happens in Parkinson's and to shed light on Dementia with Lewy bodies.

<https://www.ucl.ac.uk/drc/research/parkinsons-disease-and-dementia-lewy-bodies>

<https://weillab.com/>

Production Bios

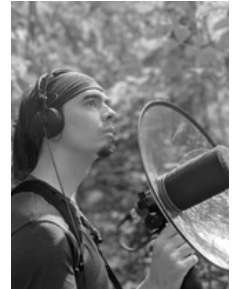
Zai Tang - Sound Designer

Zai Tang is a multidisciplinary artist based in Singapore. Drawing influence from acoustic ecology, phenomenology and electronic & experimental music, his practise is built upon a belief that listening is an invaluable means of attuning to and forming deeper relationships with the worlds we inhabit.

As a collaborator Zai plays the role of composer, sound designer and experimental musician across different context, having worked with local and international visual artists, filmmakers, choreographers, theatre practitioners, and other musicians.

Recent presentations include the National Gallery Singapore (2021); Thailand Biennale, Korat (2021); Reykjavík International Film Festival (2021) with The Migrant Ecologies Project; NTTICC, Tokyo (2020); Busan Biennale, South Korea (2020) with Rei Hayama; TPAM, Yokohama (2020) with Pichet Klunchun; Singapore Biennale (2019); Singapore International Film Festival (2019) with Simon Ball; 2nd Yinchuan Biennale, China (2018); Danspace Projects, New York (2018) with Emmanuèle Phuon. The most recent film he collaborated on {if your bait can sing the wild one will come} Like Shadows Through Leaves won the FIPRESCI Award at ISFF Oberhausen (2021) and Best Singapore Short Film at SGIFF (2021).

www.zaitang.com



Kailey Nolan - Communications Manager

Kailey is a strategic communications specialist with experience across health, research, cultural and non-profit sectors. She is committed to supporting diverse, intersectional voices; leading and facilitating initiatives to improve how people with minoritised experiences are represented, heard and supported.

