

## An Unapologetic Voice

WHERE DID YOU GO? The film  
by Jay Joseph Jones with Teepa Snow

Recently, I attended the Idyllwild International Festival of Cinema 2017 in California with Positive Approach® to Care's (PAC) Corrie Phillips. This is a very well run and respected international film festival, where my film won Best Film, Best Director, and Best Screenplay. While we were there, Corrie and I had crucial experiences that totally altered my perception of how the film provided a unique venue, when combined with audience response and personal conversations to dramatically change what is believed, known, and done related to dementia and people's lives. It is now clear to me that with greater support this short film could have a much broader effect. In this article, I hope to take things in a different direction. Here, I want to discuss some of my unshared thinking and processing behind and within the project and look at the very real impact of the film so far. I want to address why advocacy and knowledge is still very important on a wider scale and how my vision for this film was confirmed in one single afternoon in a mountain town in the USA.



Jay Joseph Jones, Director

### Storytelling is not enough

Many people understand that *WHERE DID YOU GO?* exists, but maybe don't understand why it came to exist in the way that it did and the reason why I took the approach with the team I built. In the previous month's article sent out by PAC, I spoke about how I worked closely with dementia specialists, as well as people with lived experience; people with different points of view, those living with dementia, care partners, caregivers, and activists. I noted how these were all interpreted and connected by the art of filmmaking and, in turn, how I worked to implement this learning into every aspect to depict my vision. Understanding is somewhat in the eye of the beholder; so taking on broad knowledge from different points of view to create a rounded depiction of Lewy Body dementia was crucial. At the age of 26, when I began to create this project, I knew nothing about dementia. Now, at the age of 28, thanks to the incredible team

behind me and my own instinct and insight, I have a film where I can disseminate the art on screen into situation, symptom, science, and experience. While I have no intention of sitting here and saying I am a specialist in dementia or an activist, I am an artist. Through art, and what has been experienced at screenings so far, it is now evident that this way of approaching and depicting the subject matter effectively opens the door for new audiences to view a controlled snapshot of a lesser known



Jean, played by Penelope Wildgoose,  
in *WHERE DID YOU GO?*

dementia such as Lewy Body. Audiences that wouldn't come to a conference to learn about dementia, but did actively watch a narrative short film about it, and for many, came away wanting to know more. My original goal was if people walked away from the film and conducted an internet search on Lewy Body, I felt I had done my job, but now I realize, this film can break open conversations about Lewy body and dementia as a whole with an array of different people. Which is an amazing and, as it turns out, a much-needed opportunity; something I did want to happen.

### **The Unexpected Advocacy Towards Audiences**

Why are new general and specific audiences crucial? In my journeys, so far, I have met many individuals who are living well with different forms of dementia or living beyond diagnosis with strong independence, as well as individuals that have fantastic support systems in place. However, much like the character Jean, for many individuals this is simply not their reality. I have wondered, of late, who advocates for these people? Isolated, alone, trying to catch up with what is going on with their individual brain change, no knowledge of the condition, no diagnosis. This is more common than one might think. The [\*\*World Health Organization's dementia factsheet\*\*](#) (April 2016) states that "Worldwide, 47.5 million people have dementia and there are 7.7 million new cases every year" and the [\*\*Alzheimer's International Report\*\*](#) (2016) in its foreword comments that "The huge majority of people with dementia have not received a diagnosis, and so are unable to access care and treatment." If all that wasn't enough, now also apply the common phenomena of misdiagnosis surrounding Lewy Body – let alone the challenges faced by younger onset. It's time to be frank. I would imagine one can only ever make estimations of undiagnosed individuals – I can't say for sure, I'm not a scientist or statistician. Regardless of this fact, and because this is the part that truly concerns me, people like Jean, that are simply managing day to day alone, who build a foundation of routine to mask the experiences of their brain change in order to avoid judgment of others (sometimes the people closest to them), a coping mechanism built to deal with what is really going on... I have realized that *WHERE DID YOU GO?* is the unapologetic voice not just for Lewy Body, but for those lost within all the wider points made above - that the system doesn't seek to support and instead labels. From the experiences recently had with audiences, the film offers a chance for strong advocacy and opening conversations around these topics, that would not necessarily otherwise take place. Whilst this may have always been my intent, sometimes we do not truly believe something until we live it.

The audience response to the film at the festival was overwhelmingly positive. After coming out of the Q+A sessions, I would be stopped in corridors, in the street, in coffee shops, and in burger joints. No, I am not exaggerating. For example, people would lead with "I can't forget your film, I have to ask what did this 'moment here' mean." I would answer/explain, enter discussion, and then soon after the individual would usually mention a loved one, family member, or friend/colleague who had dementia. The first time this happened, I quickly realized it was crucial having a skilled PAC team member available. Corrie would frequently assist in offering practical information and support, going beyond the artistic film-related realm into what is the reality for many. These repeated interactions became living proof that using the film to access new groups of people, different generations, and more

generalized audiences, will help further spread the word about at least one atypical dementia and what can happen without awareness or support. Offering advocacy, and beyond advocacy, knowledge is powerful. It became more and more clear that even if people were aware of dementia as a condition, the clear majority misunderstood the relationship between Alzheimers and the more global term dementia. Few, if any had **any** awareness or recognition of the possibility of something like Lewy Body dementia. By this film profiling a different form of dementia, it also opened the door for these vital conversations.

### **Beyond Advocacy, Something More**

Despite all these very important points, there was one situation that truly shocked me. Something I had not truly anticipated. Several days after the second of the four showings, I was sitting in a coffee shop working on my laptop. A woman, called Mary (not her real name) came up to me and gradually revealed during a causal conversation that she had been to see my film. Very shortly after, she also quietly self-disclosed, that for a day after the viewing she had been in a state of shock. She indicated that immediately after the screening ended, she realized that based on the symptoms and experiences portrayed in the film, what she had been experiencing might well be this phenomena called Lewy Body dementia. At this point, I immediately stopped and took stock. She began explaining how different parts of her body would suddenly not work and then be fine, how she would fall unexpectedly, or see things that “didn’t make sense.” We talked further and I recommended getting up with possible supportive assessment options and connected her to Corrie. Mary felt she had just had a lifeline thrown to her. Someone who knew nothing about what was happening for her and to her had been able to show her a possibility that could possibly change the path her life was taking. Let me say this one more time. This woman from California who simply came to the film festival for relief and in an effort to find something of pleasure, found much more. She awakened to the possibility that what she was trying to cope with and live with, and hide from others, might be a condition that had a name and could be impacted by having the right support and care. She realized for the very first time that she might have Lewy Body and not some mysterious, inexplicable, bizarre, self-induced psychosis. This came to be by watching a film. Until that moment, much of what she had was that people around her believed her to be “crazy.” This truly was a moment of insight for me. I realized I must have gotten a good bit *just right* in the film. I evidently had done my job well. The film was worth something beyond an artistic endeavor. The amazing team behind me; Penelope, Teepa, Lauren, Corrie, Robin, Kate, Jamie, Mike, Tom, Louis, Gill, Debbie, Corrine, Jayne, Freya, and Danny and so many more, all contributed towards and trusted my vision. This film offers the possibility of meaningful and valuable change for others who, like Jean, have no one to recognize what is happening and offer support that matters. Thanks to all who contributed and helped to make this happen. I really can’t thank them all enough. The last thing Mary said to me was that after the shock had subsided, she was so glad she had come, because now she had a direction to consider and a possible answer for what had been inexplicable.

Considering this, when it came to award acceptance, there was no one else to share Best Director with other than Lauren U. Thank you so much for working with me, and getting this right to help another person find what was needed to take the first step in

finding acceptance and a community of support. In light of this, and with Teepa's permission, I asked Gill Maidens to offer an article for the Journal this month. A special thank you to the Festival Director and Producers Stephen Savage, Trinity Houston, and Andrea Charles, and to The Film Festival Doctor for recommending this festival.

### **Why we fundraise**

The time in Idyllwild convinced me, more than ever, that further fundraising to promote and expand the film's visibility is vital. This is why I continue to seek support and funds.

We are asking for your assistance. To help cover campaign costs (travel expenses, administration, festival submissions, and marketing), to get a PAC team member and myself to be present and available, to keep spreading both artistic advocacy and knowledge, to have conversation after conversation, and to conduct Q&As screening after screening. Without your help it will not be possible, so please provide financial support to enable this film's campaign. Together we can reach new audiences, new communities, and unsupported people living with dementia, in a way that nothing else can. Thank you for taking the time to read and consider. Donations are collected by the not-for-profit production owner of *WHERE DID YOU GO?*, [\*\*Shared Syndicate C.I.C.\*\*](#), or you can make your donation via the [\*\*Dementia Spotlight Foundation\*\*](#).



Jay accepting the Best Director award at Idyllwild