

**BEFORE WE FORGET AN INTIMATE LOOK INTO THE LIVES OF
TWO ASIAN WOMEN WITH DEMENTIA AND THEIR FAMILIES**

Presented by Hachisu and the Lien Foundation



TRT: 54 minutes
Rating: PG (Parental Guidance)
Language: English with English & Simplified Chinese subtitles
Website: www.beforweforget.org/documentary

When Jeremy Boo, 22, and Lee Xian Jie, 21, realised that the only way to reduce the stigma of dementia, which perpetuates myths and ignorance, is to put a human face to it, they filmed for a year the lives of two families and their journey with dementia.

“It is clear that neurological disorders will be the scourge of our generation, and dementia is going to overwhelm our society,” says Jeremy. “Many dramas and movies have portrayed people with dementia as lost or ‘blank’, and make the disease larger than the person suffering from it,” says Xian Jie. “We want to change this with stories from real people and an insightful documentary”.

A trailer is now on [Vimeo](#) and [Youtube](#). The documentary will be released in late 2012.

SYNOPSIS

Even as Joyce Fernandez devotes her life to care for her mother, Celine, who suffers from Alzheimer's Disease, she fights her fears with faith when her mother's health worsens rapidly. Meanwhile, Dr Irene Giam, who describes herself as an atheist who does not fear death, struggles to restrain her emotions in a relentless march with vascular dementia. Intimate and unflinchingly honest, BEFORE WE FORGET is a film of two women with dementia who live in an Asian society where terminal illnesses and dying remain taboo.

LONG SYNOPSIS

Filmed in an observational style, BEFORE WE FORGET is the interwoven story of two Singaporean families and their yearlong journey with dementia. The film tells the story of Joyce Fernandez, a 50-year-old woman caring for her mother Celine, who has had Alzheimer's Disease for 7 years.

When Celine suffers a mild stroke and is hospitalized for over three months, Joyce attempts to keep herself together especially after Celine lost all what little speech and she originally had. "Mum and I would have good conversations. But not anymore. I didn't lose a mother, I lost a friend". The duo, staunch Catholics, keep their heads above the emotional turmoil through daily prayer.

The documentary also captures frank interviews with Dr Irene Giam (PhD), a former mathematics tutor and atheist with strong views about death in the face of terminal illness. She is first filmed after being diagnosed with 'mild cognitive impairment' likely due to systemic fibrosis, an autoimmune disorder which affects her breathing. After she is warded in a hospice because of her rapidly worsening health, vascular dementia causes her to forget the frequent visits by her husband and deepens her feelings of loneliness.

Intimate and unflinchingly honest, BEFORE WE FORGET is a film of two women with dementia who live in an Asian society where terminal illnesses and dying remain taboo.

QUOTES

Before We Forget is a very well made film on a very important subject. In this materialistic, consumerist world we live in, dementia is something people should be talking more about.
Alex Au, Yawningbread.org

I look forward to more sensitive Singapore-related films, from a new set of eyes!
Juan Foo, Media Development Authority

Meeting Jeremy and Xian Jie was one of the highlights of my working experience, and the film continues to fill me with much encouragement.
Dr Chris Lien, Geriatrician

DIRECTOR'S STATEMENT

We embarked on this project for two reasons. The first is that we believe that neurological disorders will be the cancer of our generation. While we have treatments for cancer today, we do not have any effective treatments for neurodegenerative diseases, which are chronic and terminal. To exacerbate matters, these disorders will only rise with an ageing population.

The second reason stems from Jeremy's personal experience of taking care of his mother who has Amyotrophic Lateral Sclerosis (A Motor Neurone Disease; ALS is also known as Lou Gehrig's Disease). Caregiving, he slowly realised, is not a one-dimensional affair. While he expected sorrow and grief, he was not prepared for anger, guilt, denial, and physical, mental, and emotional exhaustion. These emotions run in a circle, drawing in tighter and tighter, feeding off each other. Neurodegenerative diseases do not affect just the person with it, but also the loved ones of that person.

When we were looking for subjects for this story, we realised that many are not willing to come forward because of the stigma of mental illnesses (even though dementia is not a mental illness) and end-of-life issues. Out of about 20 potential subjects, only two families welcomed us into their private life.

This stigma makes it more difficult for people to learn more about dementia and stifles conversation about end-of-life issues. Consequently, we hear of stories of people with dementia locked at home because their children do not understand why their parents are wandering outside; people with dementia who have to be restrained to their beds because they keep pulling out feeding tubes that were inserted, even though there is no evidence that feeding tubes necessarily improve quality of life; people with dementia who are sedated and intubated, alive only because of machines that pump blood, and forces air into their lungs.

When we made this documentary, we wanted to observe, for a year, the lives of people with dementia and their caregivers. We merely wanted to tell the stories of these people so that others may understand and empathise with them.

We are under no illusion that this documentary will provide a cure or a solution. But we are convinced that this documentary, coupled with www.beforeweforget.org, will foster conversations about dementia and end-of-life issues and it is these conversations that will make the lives of people with dementia and their families more comfortable.

The 48 shooting days produced intimate observational footage that ran to close to 100 hours. We kept the documentary as observational as possible, with few titles and no background music or narration. We used only scenes that advanced the storyline and avoided stylistic supplemental footage, which are beautiful but essentially useless.

There is no contrived message, statement, or morale in this documentary. Whatever message or morale stems from the viewer's own experiences and we encourage the viewer to share these thoughts and feelings with others.

Jeremy Boo & Lee Xian Jie

TECHNICAL NOTES

BEFORE WE FORGET was filmed using a Canon 5D Mark II on location in the homes of both families, in hospitals, and in a hospice from August 2010 to August 2011. As people with dementia are easily distracted, the HD DSLR setup allowed us to unobtrusively film throughout the day because it did not look intimidating.

Although it was an economical camera compared to other videocameras with 1080p recording, it also created many problems. To help other filmmakers make their own equipment selection choices, we will describe how we overcame its limitations:

Rig. For stabilisation, the 5DMK2 was mounted on a Genus Shoulder Rig with Follow Focus with a quick-release, but in public and in hospitals, the 5DMK2 alone was used to record covertly (although permission had been given) so that other patients and members of the public would not be alarmed by the presence of a documentary crew.

Going rig-less. We ditched the rig whenever we did not want to lug around a massive bag (which was prone to security checks at train stations), put all our gear into the more portable Domke F-2 canvas bag, and resorted to shooting on an extremely wide lens for stability.

Lenses. Most of the footage was filmed on the extremely wide Canon 16-35mm f/2.8 L USM, which allowed us to capture multiple layers of interest within a single frame, and remain close to our subjects without stabilization issues. The Canon EF 85mm f/1.8 and Canon 70-200 F2.8 L IS USM were used in other scenes.

Camera settings. We recorded in full-HD, 24fps. Indoors, the shutter was set to 1/50 to achieve a cinematic look. Outdoors, it was frequently f/18 or smaller, and when that was not enough in the bright tropical sunlight, the aperture was dialed down to f/11 or smaller. Our research showed that current models of variable ND filters cause uneven coverage in bright conditions at times.

Audio sync. Audio was a major problem because we did not have a pre-amplifier to boost signal input to the camera for sync sound. Because of its small size, the on-board microphone produced low-quality sound we could not use. We decided on dual-system sound recording, synchronized in post-production with PluralEyes for Final Cut Pro.

Microphones. The on-board microphone of the camera was used for synchronisation in post-production with audio from the cleaner-sounding Sennheiser G2 Wireless lavalier microphone recorded on a Zoom H4N. A RØDE NTG 3 (in a blimp) was used sparingly and only during some interviews because being large and furry, it was too much of a distraction for our subjects.

Media storage. We carried around three Sandisk Extreme 32GB 60MB/s CF Cards. Initially an external 4TB hard drive (RAID 10) connected to a MacBook Pro with an OWC 34mm ExpressCard port to eSATA adapter seemed adequate. But we gradually ran out of space with the vast amount of footage and sound recording, so later we re-configured it as a RAID1 array and added another 8TB RAID1 array as backup.

Editing. The camera produced H.264 files, which we had to convert into an editable format like ProRes 422 LT. MPEG Streamclip and FCP Compressor on a 2.4 Ghz MacBook Pro, 4GB RAM took days for conversion. Rendering and exporting the final cut also took a long time.

DIRECTORS' BIOGRAPHY

Jeremy Boo, 22, and Lee Xian Jie, 21, are humanitarian reporters and documentary filmmakers. They are [Ngee Ann Polytechnic's Mass Communication](#) graduates and were editors for the student newspaper and online lifestyle magazine.

They have photographed and written stories about the Burmese community in Singapore, [arsenic-contaminated waters in Cambodia](#), [slums in Manila](#), among others. Their work have been published by [The Straits Times Saturday Special Report](#) and [Reader's Digest Asia](#).

In 2010, The International Committee of the Red Cross (ICRC) selected Jeremy as a winner of the [ICRC Young Reporter Competition](#), and flew him to Georgia to report on the decade-long conflict.

Jeremy and Xian Jie run [Hachisu](#), a communication and production house that makes issues more human with good writing and design. In this way, they create conversations people remember and love.

ABOUT BEFORE WE FORGET

Before We Forget is a youth-led initiative to foster conversations about dementia in Asia, and is supported by the Lien Foundation's Life Before Death campaign. Three [public multimedia exhibitions](#) held in September 2011 drew more than 15,000 visitors, and a [website](#) has been set up to collect stories from people who have been affected by dementia.

ABOUT THE LIEN FOUNDATION

The [Lien Foundation](#) is a Singapore philanthropic house noted for its model of radical philanthropy. It invests in innovative solutions, convenes strategic partnerships and catalyses action on social and environmental challenges. The Foundation drives institutional capacity building to address crucial community needs, and empowers individuals to reach their full potential. It seeks to enhance educational opportunities for the disadvantaged, excellence in eldercare and environmental sustainability in water and sanitation.

The Foundation advocates better care of the dying as part of its mission to advance eldercare. It first conceived and spearheaded the [Life Before Death](#) initiative in 2006 to create greater public awareness about end-of-life issues in Singapore. Since then, the Foundation has continued its drive to highlight the urgent need for improved care for the dying. It also sought to de-stigmatise death and dying by spurring 'die-logues' amongst the public. In 2010, the Foundation commissioned the Economist Intelligence Unit to conduct the first-ever global [Quality of Death index](#) ranking 40 countries on their provision of end-of-life care.

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