

DOMINI FORSTER

DIRECTED BY SUSIE FORSTER

SOUND EDITOR STEVE NOSSITER



A feel good documentary about dying at home

#### contents

one liner	3
<u>synopsis</u>	
one pager	
the filmmaker.	
impact	
music	
technical details	
screener link, trailer link. media & distribution.	
press release.	
media coverage.	
more info and resources on palliative care.	



#### one liner

In an act that some would consider radical, and certainly highly personal, a filmmaker captures her family's most intimate moments together at the end of her mother's life, as they help her to die at home, surrounded by her art, in the Australian bush.

### synopsis

When Victorian artist Lee Stephenson discovers she is dying and requests, in no uncertain terms, to die at home, her daughter, a filmmaker, captures this extraordinarily personal window into the last two weeks of her life. Shot at "Longlee", her mother's art-filled home in the stunning Goulburn Valley, we witness the 82 year old artist navigate her impending death, veering between grace, anger, clarity and confusion. We meet Susie, daughter and intrepid filmmaker; Roger, the practical and attentive husband, and Domini, Lee's insightful singer/songwriter granddaughter. In unusually intimate footage, they disclose their real feelings about seeing Lee dying, paint a picture of how close she came to refusing medical help and how the eventual doctors visit triggered the state-funded palliative care. We see the generosity of spirit of the home care support team and Roger drawing on his farming background to care for his dying wife. Domini shares her shock at seeing Lee 'this sick', while still at home in her own bed - one now swapped out for a hospital bed (a "must-have" for anyone dying at home, according to the palliative care team). We meet an almost unrecognisable younger Lee, showing off her garden in footage shot 16 years earlier. With love, humour and sadness, and in the thick of COVID restrictions, they work together to grant Lee her final wish - to die at home.



#### one pager

Lee Stephenson is dying. At 82, she's largely evaded doctors and hospitals, living a secluded life on a bush property, in the Victorian Goulburn valley. Her house is filled to the brim with her own paintings of the landscape and garden she loves. Now, in the midst of COVID restrictions, having long ignored symptoms of ill health, and losing weight fast, she senses her days are numbered. Her daughter, the filmmaker, recounts how her mother phones her in NSW one day, to say she wouldn't mind if she woke up dead.

Lee initially refuses to see a doctor, but as fate, and ultimately her family, would have it, the doctor intervenes and Lee finds out she is in the last stages of cancer. She must relinquish control of her life, but where she will die is not negotiable.

Lee's greatest wish is granted through her husband, Roger. He takes to the task of nursing his wife in the same kind of practical way he's looked after farm animals and machinery for most of his life. Worrying over Lee's ability to swallow, Roger recounts how he's seen lambs drown while being bottle fed, when their swallow reflex gets confused. Despite feeling helpless as she surrenders the fight, he reports feeling closer to Lee than he has for a long time.

As games of summer tennis flicker on TV screens in the house, Lee relinquishes the care of her garden to other less knowledgeable gardeners and an old friend visits to reminisce about their time on the land. Domini, Lee's insightful granddaughter and professional singer/songwriter, performs a new song she is writing on acoustic guitar in the family dining room. She shares her shock at seeing Lee 'this sick', while still able to be in her own bed. Susie reports finding it surprisingly straightforward to care for her dying mother, despite not having previously experienced a close relationship with Lee.

We see home video footage shot by Susie 16 years earlier, featuring an almost unrecognisable Lee, robust and vital, showing off her garden. She is in full hostess mode, displaying her extensive knowledge on plants and animals, including some vastly mature pets, themselves surely living on borrowed time.

The Lower Hume Palliative Care team assist with everyday care and pain medications for Lee, in a time of increasing COVID restrictions. There are sensitive discussions with Lee about death. Their help, and the home-delivered hospital bed, is invaluable to the family as Lee's body and mind gradually wind down and the waiting game begins. 'I must die soon', declares Lee, to the district nurse, Christine.

Shot with an intimacy rarely seen on film, this participatory documentary reveals layers of beauty amongst the gritty reality of dying. We sense it through humorous day-to-day moments; the caring of the support crew; in the stunning landscape; in Lee's striking paintings and the poignant original folk song performed by her granddaughter in her dining room, only days before Lee's death.

Curious magpies and haunting currawongs bear witness as Roger and Susie recount their last moments with Lee. After her death, tears, some long held back, are shed. David, Susie's partner, helps the cremation service staff to remove Lee's body, leaving the bedroom strangely empty. The family each plant a tree to mark her death- the departure of a woman who has been a fixture of everyone's lives- and never more so than for the last two weeks.



#### the filmmaker

**Susie Forster** is a director/producer, editor and shooter who creates documentary films that focus on social adversity, environmental challenges, disability and other underrepresented subjects in mainstream culture. She has shot and produced a number of award-winning short films and co-produced the celebrated feature doc *The Bentley Effect*. She describes her style as "observational and lyrical documentary filled with an intimacy that reveals the subject's inner world". She frequently collaborates with her daughter, singer/songwriter Domini Forster.

This film surpasses any of her previous work for hitting close to home. Begun as a way to record the quirky conversations she found herself having with her dying mother, she soon realised that she was capturing a window into a time of life that is rarely viewed so closely. Surprised by amount of palliative care support available to the family, and seeing that her mother was not adverse to being recorded, her stepdad agreed with her that a film could help more people learn about the benefits and accessibility of palliative care at home. Together, and with the support of the extended family and the palliative care team, they help to give Lee the death she wanted.

In an act that some would consider radical, and certainly highly personal, she shares with us some of her family's most intimate moments together, at the end of her mother's life.



# impact- preparation for dying by raising awareness of family supported palliative care at home

The reality of death is a subject often avoided in Western society, leading many of us to approach our own mortality, and that of those we love, with a fair amount of trepidation if, indeed, we consider it at all. This head-in-the-sand approach means that choices about where and how we die are often made for us, without us being aware of our options. In Australia, one of those options is state funded palliative care at home, which offers us the chance to care for a loved one at home, as they die safely and peacefully, with the support of trained nurses and carers, and in a hospital bed with special equipment.

A film like this has the power to start conversations, raise awareness of our options around dying and can help to lessen the fear of death. One of things the film encourages is communication about what we want with our loved ones, and leads the audience to consider various palliative care options. The film emphasises the value of a hospital bed as an essential element of palliative care at home. The bed allows far greater comfort and mobility to a dying person. The filmmaker mentions a course available on the North Coast of NSW, designed to help prepare people for dying naturally and helping others when they are dying.

The audience sees not only loss, but also joy and connection. We can sense the benefits experienced by those who are left behind by the end-of-life situation that we see on screen. Families may feel empowered to consider caring for their loved ones themselves, and may seek information about the available palliative care in their area. Dying at home is an option we could have for the end of our life, and this film poses these questions- how will we choose to live as we die; where will we be and who will look after us?



#### music & soundtrack

**Domini Forster's** music provides a delightful diegetic sound layer to the film, as she attends Lee's bedside, helping her mother and step-grandfather care for Lee. One afternoon, sitting at the dining room table, Domini performs a folk song on guitar that she is in the process of writing. Titled "Gravity", it's delicate and gently heart-breaking lyrics hint at the suspension and inevitable pain of loss, and the experiences of intimacy and of drifting apart. She shares with her mother the shock she experiences in seeing how much her normally active and capable grandmother had changed since she got sick.

"Then You Stop", a track from her second album, Raven, takes the film out, as Lee's body is carried out of her room. The theme of the suddenness and strangeness of death in the song describes some of what we have seen take place, and highlights a simplicity and frankness to the finality of Lee's death.

#### About the singer/songwriter

Domini Forster leads you through the dusk-lit corridors of her intricate song- stories, each scene as intimate and lovelorn as tea-stained lace. Forster's distinctive voice shifts effortlessly from commanding call to lilting, whisper-close falsetto, earning her comparisons to the likes of Laura Marling and Joni Mitchell. Over recent years Forster has toured extensively with renowned Australian singer-songwriter Lior, and the pair recently formed a collaboration project on the strength of their intrinsic connection as singers.



#### technical details

**Genre:** documentary

**Running time:** 72 minutes

**Director/producer:** Susie Forster

susie@byronbaymultimedia.com.au

Music: Domini Forster

dominiforster.com

Format: HD 1080p

**Production company:** Byron Bay Multimedia

byronbaymultimedia.com.au

Language: English

Date of completion: June 2023



watch the trailer here



watch the screener here

password: please contact us for this

### media & distribution enquiries



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# A feel-good story about death - at home

Not many of us have lived with a loved one at home as they die. Those who have are likely to be changed forever by the experience. Candid and highly personal, this 72 minute documentary unflinchingly reveals the last two weeks of the life of Victorian artist Lee Stephenson, whose abundantly clear wish to die at home is granted with the support of her family and a local palliative care team.

Shot by Lee's daughter, Susie Forster, this film surpasses any of the filmmakers previous work for hitting close to home. Begun as a way to record the quirky conversations she found herself having with her dying mother, she soon realised that she was capturing a window into a world that is rarely viewed. In an act that some would consider radical, and certainly highly personal, she shares with the audience some of her family's' most intimate moments at the end of Lee's life. Forster says,

"Dying is not a bad thing. Mum wanted to die. And what was very clear is that she wanted to die at home, and it was enormously satisfying to be able to give her that."

Death is a subject we often avoid in Western society, leading many of us to approach our own mortality, and that of those we love, with a fair amount of trepidation, if indeed we consider it at all. This head-in-the-sand approach means that choices about where and how we die are often made for us, without us being fully aware of our options. In Australia, one of those options is state funded palliative care at home, which offers us the chance to care for a loved one as they die safely and peacefully, with the support of trained nurses and carers, in their own home.

For most of Lee Stephenson's 82 years of life she evaded doctors and hospitals, living a secluded life in the Victorian Goulburn valley. In the midst of COVID restrictions, having long ignored symptoms of ill health and now losing weight rapidly, she senses her days are numbered. Her daughter recounts how her mother phones her one day to say 'she wouldn't mind if she woke up dead'.

In the film we meet the Lower Hume Palliative Care team, who assist with everyday care and pain medications for Lee. Some take part in sensitive discussions with her about death. Their help, and in particular, the hospital bed, is invaluable to the family. Christine, one of the nurses describes the elements of what she calls "a good death", something to which they all aspire to:

"I think the best thing that we can aim for is just what we call a 'good death', which really involves having family and close friends around"

Shot with an intimacy rarely seen on film, this participatory documentary reveals layers of beauty amongst the gritty reality of dying. We sense it through humorous day-to-day moments; the caring of the support crew; in the stunning landscape; in Lee's striking paintings of the countryside and her garden and the poignant original folk song played by her granddaughter in her dining room, only days before Lee's death.

Don't miss sharing this sometimes confronting and often touching view of the everyday trials and tribulations of this unrehearsable process- living while dying at home.

### media coverage

Film Review

https://www.thesenior.com.au/story/8224162/melbourne-documentary-film-fest-offers-plenty-to-reel-in-seniors/



Video interview with Melbourne film critic Peter Krausz

https://www.youtube.com/watch?v=o2OBmacokqw&ab\_channel=PeterKrauszMovieMetropolis



Radio interview with Annie McLoughlin at Melbourne station 3CR

https://www.3cr.org.au/sites/default/files/show/user357/The%20Last%20two%20weeks%20at%20Longlee.mp3?fbclid=IwAR0QG3CbP\_9VceTF5omkH2RfxlgTAzglzmKZ4jLS3b2LCDNF06EPgEMIk2k

# more info & resources on palliative care in Australia

#### From the Australian Government, Department of Health and Aged Care

Data published by the Australian Bureau of Statistics suggests around 50% of all deaths in Australia occur in a hospital, with the remaining 50% occurring in other settings, including within residential aged care facilities or a person's home in the community. This data includes people who have been diagnosed with a life limiting illness.

The Australian Government is committed to ensuring all Australians diagnosed with a life limiting illness can access quality palliative and end of life care, to enable them to die with dignity, free from pain, and supported in their choice of where they may wish to die. As part of this commitment, the Australian Government provides funding to the states and territories, through the National Health Reform Agreement, to support the delivery of palliative and end of life care across the country. How these services are delivered within each jurisdiction is the responsibility of the individual state or territory government but does include the provision of palliative care services at home. It also may include the provision of aids and equipment such as hospital bed, to enable a person to stay at home to receive care, noting that this type of support is determined and managed by health services within each jurisdiction.

Additionally, the Australian Government also provides funding for a wide range of national projects and programs that aim to improve access to palliative and end-of-life care for all Australians so they can receive the care they need, where they want, including at home. Some of these projects and programs are:

- <u>Caring@Home</u> provides evidence-based and practical information for health professionals to assist and support families and carers of individuals with a life-limiting illness to be cared for and die at home if that is their choice. This includes resources to support carers and families to help manage end-of-life symptoms for a person at home including safely using subcutaneous medicines
- <u>Carer Help</u> is a freely accessible website providing information and resources to better support
  Australian families caring for someone with an advanced disease. The current project aims
  improve support for rural families caring for someone with an advanced disease
- Greater Choice for At Home Palliative Care provides funding to the Primary Health Networks to employ dedicated staff to coordinate activities to improve access to palliative care in primary and community care, based on the specific needs of their region.
- You can find more information on other palliative care programs and projects on <a href="the-beatth">the-beatth</a> Department of Health and Aged Care's website

# more info & resources on palliative care in Australia — cont.

In addition, under the current aged care system, the Australian Government supports older people to remain living at home through either the Commonwealth Home Support Programme (CHSP) or a Home Care Package (HCP). The CHSP is an entry-level aged care program for frail, older people aged 65 years and over (or 50 years and over for Aboriginal and Torres Strait Islander people) who need some help with daily tasks due to their functional limitations. However, where a client has more complex needs, they may be better supported by a HCP. These aged care supports are not intended to replace palliative or end of life care (or other health services) but rather work alongside these services, to enable an older person to remain living at home wherever possible. For further information on aged care supports, please visit My Aged Care

#### Zenith Virago- Deathwalker training, as referenced in the film https://www.zenithvirago.com/

