

Pulse of My Heart, Edie Mayhew Fellow of the Elder Leadership Academy

Title: Pulse of My Heart

Fellow: Edie Mayhew

Date: 2015 – 2019.

Context

In 2015, Edie was interviewed for a research project called Still gay ..., the project documented LGBTI people's experiences of dementia. The words and photographs Edie shared were used to produce an iMovie, which Edie co-directed. The response to the film was so positive it inspired a series of films documenting Edie's journey with her wife Anne Tudor. Edie wanted to share her story to educate other people about dementia.

A further three films were produced, with Edie taking a less active role as her dementia progressed. Edie died in 2019; we miss her so much and love that she still has such a powerful role in our lives through the films.

Edie's project is called Pulse of my Heart, or 'A chuisle mo chroi'. This is an Irish Gaelic expression meaning 'my darling, my love'. The title reflects the love that Edie and Anne have for each other.

Aims and objectives

To humanise the experiences of people living with dementia by educating service providers and the broader community to understand the importance of love and connection in the lives of people living with dementia. This was achieved by producing a series of films documenting Edie's journey living with younger onset dementia, and her relationship with her married partner Anne Tudor.

Activities

1. Developed a story for the Still Gay report, Australia's first research/resource on LGBTI people's experience of living with dementia
2. Documented a narrative and shared photographs for A Day in The Life of Edie (first film) showing Edie engaged in everyday activities
3. Recorded Our Hearts Are Bigger (second film) where Edie and Anne are filmed opening and reading love letters they wrote to each other when they

spent a week apart. Film launched at the Eureka Centre, Ballarat with 150 guests

4. Recorded The Circle of Love (third film), a re-commitment ceremony celebrating Edie and Anne's relationship. The ceremony took place during the 2018 Marriage Equality Postal Vote in Australia. Edie and Anne and Edie were able to marry several months later, when marriage equality was approved
5. Pozible Campaign to raise funding for a fourth film, Mr Velvet Ears, which saw over 100 people donate 11,600 to support the film. The film documents Edie's transition into residential aged care
6. Series of launch events for Mr Velvet Ears included a
 - a. Ballarat launch, Little Square Garage
 - b. Mercy Place, Ballarat (Edie's aged care home)
 - c. The Wheeler Centre, Melbourne event
 - d. Out in Perth event ([here](#))
7. Premier events for Mr Velvet ears included plenary showing at
 - a. The 2021 Alzheimer's New Zealand Conference ([click here](#))
 - b. The 2018 Hammond Care International Dementia Conference in Sydney

Outputs (at 2021)

- 2019: [Mr Velvet Ears](#) – trailer viewed 1,633 times (first 3 years) and 430 people at launch events
- 2018: [The Circle of Love](#) - film viewed 499 times (first 3 years)
- 2017: [Our Hearts are Bigger](#) - film viewed 779 times (first 4 years)
- 2016: [A day in the life of Edie](#) - viewed 5458 times (first 5 years)
- Media stories include:
 - Australian Ageing Agenda ([here](#))
 - Ballarat Courier ([here](#))
 - Community Care Review ([here](#))

Outcomes

- Over 2500 unique visitors to the Pulse of My Heart website
- Mr Velvet Ears has premiered at International Dementia Conferences
- The 2017 film became the focus of a [Letters of Love and Dementia Campaign](#) - with dozens of letters shared from around the world on the human experience of living with dementia
- Mr Velvet Ears has been shown by dozens of Councils and Carers Groups for Carers or Dementia Awareness week

Links: [Pulse of My Heart](#) webpage