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# An Exploration of Stories of Older Persons and Family Members Living with Dementia

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## Introduction

The Welsh Government's (2017) Social Care Research and Development Strategy for Wales 2018-2023 notes that dementia is one of the largest health and social care issues in Wales. There are currently 22,000 people living in Wales with a dementia diagnosis (Alzheimer's Research UK, 2018) which costs the Welsh Government £1.4 billion per year (Alzheimer's Society, 2017).

The dementia trajectory is unique to each individual (Andrews et al., 2017), therefore, it is important to give the "real people" a say over the care and support they need (Social Care Wales, 2018).

Life story work has been used in various health and social care settings (Hewitt, 2003) as it uses information about the person's past, present and future hopes to improve their current situation (Murphy and Moyes, 1997).

## Aims

- 1) To explore and understand the lived experiences of people with dementia
- 2) To understand the experiences of family members of people with dementia



This study stems from a year-long KESS Master's by Research project conducted in partnership between USW and Hafod Care Association entitled "**An Exploration of Stories or Narratives from Older Persons Living with Dementia**".

The previous study demonstrated that life story work is a successful data collection tool for people with dementia as it provides rich, meaningful and unique information about life with the disease.

## Methodology

**Design:** This is a descriptive phenomenology study aiming to understand individuals' experiences of living with dementia, without preconceptions, through the use of narratives and stories.

**Participants:** It is estimated that 15 people with dementia and 15 family members will take part in this project. All of the participants with dementia will be 65+, aware of their diagnosis, able to give full informed consent and receive care and support through CTUHB and ABUHB.

**Materials:** All participants will be video recorded whilst providing their life stories. All research documents will be made "dementia friendly".

**Ethics:** This project is currently going through the ethical processes.

**Analysis:** The videos will be transcribed, edited by the participants for accuracy then analysed using Colaizzi's (1978) descriptive phenomenology analysis framework.

## Results

Results from this project may be used to:

1. Educate people about life with dementia.
  2. Improve the care and support services offered by CTUHB and ABUHB for both the person with dementia and their family members.
  3. Demonstrate that people with dementia can reliably take part in research.
- This project will be written up as a PhD thesis..

The video recordings will be edited, with the addition of music and photographs to create "this is your life" style documentary DVDs for the participants to keep.

The DVDs can be used by care staff, alongside traditional paper based care plans to see the person past the dementia (Batson et al., 2002).

The DVDs may also hold a sentimental value for the family members after their loved one has passed away (Benbow and Kingston, 2016).

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**This is a PhD Research Project which is due to be completed in October 2020**