

## SELF FUNDED PHD OPPORTUNITY

### Experiences, needs, interventions and outcomes of family carers of persons with dementia

#### Project Details:

#### **Applications are invited for a self-funded PhD relating to the experiences, needs, interventions and outcomes of family carers of persons with dementia.**

The Association for Dementia Studies, University of Worcester is seeking self-funding PhD students to work on a programme of research around the experiences, needs, interventions and outcomes of family carers. This programme is being led by Dr Tracey Williamson, Dementia Carers Count Professor of Family Care in Dementia. As a new programme the exact focus of the proposal can be student-led so long as it reflects an element of:

- Caring for people with different types of dementia, different symptoms, different dependency levels and how these change over time.
- Caring for people with different emotional dependencies, different practical needs, different physical needs and how these change over time.
- Way in which carer factors such as age, gender, class, ethnicity, migration, sexual orientation, employment impact on caring for persons with dementia.
- Way in which relationship factors impact on caring such as differences between person with dementia and adult child, spouse/partner, siblings, parent (Learning Difficulty & Young Onset Dementia), living together, living in separate dwellings, amount of contact
- Way in which relationship history such as loving relationships, abusive relationships, attachment and dependency issues and dislocations can impact on caring for someone with dementia.
- How the carer's social network and relationship with others impacts on care experience such as spousal relationship, children, grandchildren, siblings, friends, confidants, social, spiritual and community networks.
- Differences between carer personality and resources factors such as emotional resilience, personality type, mental health, physical health.
- Transitions such as move to care setting (hospital, care home, Extra Care), in and out of employment, occupation of ex-carers e.g. volunteering, community activism.
- Interventions such as courses, support/therapy, technology, activities, bereavement care, respite.
- Outcomes that lead carers to thrive, cope, survive, leave, drown

#### Context:

There are known to be 850,000 people living with dementia in the UK (1) with 700,000 family carers providing support to those persons. Carers can face significant challenges as the demands of caring increase over time (2), with some carers able to care until a person's end of life, whereas others go through the transition to care home life for the person they care for. Along the journey there can be major events such as hospital admission for a carer or person with dementia. There can also be very different experiences of service provision depending on such things as geographical area or because available services target some groups to the exclusion of others. For example provision of support groups and services aimed at families experiencing young onset dementia has grown in recent years yet these initiatives were previously far and few (3). Individuals identifying with a particular

community e.g. the LGBT community may also feel their needs are not well met when in a caring role or as a person with dementia. Greater understanding of diversity issues in relation to dementia family carers is needed. A range of interventions aimed at supporting or enhancing the wellbeing of family carers have been developed (4), but as more are developed there is a need to understand what works and why, for whom and in what context as well as the cost-effectiveness of these.

Growing recognition is being given to the effects of caring upon carers who are in employment (5, 6). These carers often choose, or feel forced, to reduce their work hours or give up work altogether to care for a family member with dementia. This can have a detrimental effect on the income of those carers to care for the person with dementia, other dependents such as children and themselves.

Caring for a person with dementia can be very rewarding and family carers benefit from learning practical and psychological strategies to better equip them to care. A range of courses for carers of people with dementia is emerging in response to the growing recognition that carers need help to equip themselves with the skills and knowledge needed to care along with building resilience and techniques to combat stress (7). Maintaining the health and wellbeing of carers is important in part to enable them to undertake their caring role well and to minimise their use of health and social care services, but also because it is the compassionate thing to do. There are a growing number of interventions provided for carers including breaks, therapy and online support. Technology is also increasingly seen as an aid to organising care and maintaining safety of the cared for person, which in turn may reduce stress on the carer (8).

#### **Supervisory team:**

##### **Director of Studies:**

Professor Tracey Williamson, Association for Dementia Studies

##### **Supervisors:**

Dr Shirley Evans, Association for Dementia Studies

Isabelle Latham, Association for Dementia Studies

This PhD provides an opportunity for making a significant contribution to the developing evidence base for family carers of persons with dementia. As a relatively underdeveloped field compared with research relating persons with dementia, and due to this being a new research programme at the university, there is a broad range of potential topics to research which fit with the proposed aspects of family carers identified above. Potential applicants would work closely with the Director of Studies to agree the exact study focus and methodology. First-hand experience of a caring role (paid or unpaid) would be advantageous.

#### **Costs:**

Some travel costs are likely to be incurred (Total approx. £600)

**Methodology:** To be appropriate to the research focus – qualitative, mixed methods and participatory approaches welcomed.

## **References:**

- 1 Alzheimer's Research. Alzheimer's Society 2017. London.
- 2 De Waal H, Lyketsos C, Ames D, O'Brien J. Designing and Delivering Dementia Services. Cambridge. Wiley Blackwell. 2013.
- 3 Withall A. The Challenges of Service Provision in Younger-Onset Dementia. *Journal of the American Medical Directors Association*. 2013: 230-232.
- 4 Dam AEH, de Vugt ME, Klinkenberg IPM, Verhey FRJ, van Boxtel Martin PJ. A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas*. 2016; 85: 117–130.
- 5 Alzheimer's Research. Alzheimer's Society 2017. London.
- 6 Luscombe G, Brodaty H, Freeth S. Younger people with dementia: diagnostic issues, effects on carers and use of services. *International Journal of Geriatric Psychiatry*. 1998; 13.5: 323-330.
- 7 Morris L, Horne M, McEvoy P, Williamson T. Communication training interventions for family and professional carers of people living with dementia: a systematic review of effectiveness, acceptability and conceptual basis. *Aging and Mental Health*. 2017. 22.3: 1-18.
- 8 Powell J, Gunn L, Lowe PK, Sheehan B, Griffiths F, Clarke A. New networked technologies and carers of people with dementia: an interview study. *Ageing and Society*. 2010. 1073-1088.