

## 2017/2018 Summer Studentship Project Application Form

Send to: Research Office, University of Otago Christchurch, PO Box 4345, Christchurch, by 5pm on 3 July 2017

### Supervisor Information (First named supervisor will be the contact):

First **Supervisor's** Name and Title: Ms Tracey Hawkes

Department - UOC &/or CDHB (if applicable): CDHB

First Supervisors Phone: 027 257 9531

Email: tracey.hawkes@cdhb.health.nz

First Supervisors Mailing Address: Portacom A Burwood Hospital, Burwood Rd, Christchurch 8083

Co-Supervisors Name and Title(s): Dr Susan Gee, Dr Matthew Croucher

### Research Category (Choose one category only – to be used for judging the students' presentations):

Clinical

Laboratory

Community X

### Project Title (20 words MAXIMUM):

Enriching the environment for people with Down syndrome living with a dementia

### Project Description:

#### INTRODUCTION

As the life expectancy of people with Down syndrome has increased dramatically with better health care, there is an increasing number of middle-aged and older people with Down syndrome. Down syndrome is a condition in which a person is born with extra genetic material from chromosome 21, typically with three copies instead of the usual two. The extra copies of genes present in Down syndrome cause developmental and health issues. In addition, three of the genes associated with Alzheimer's type dementia are located on chromosome 21. The result is that people with Down syndrome develop the brain changes associated with Alzheimer's disease as they age. They are more likely to develop the clinical signs of dementia and for these to develop at an earlier age than in the general population. About a third of people with Down syndrome who are in their 50s have dementia (Alzheimer's Society UK; Dodd et al., 2009).

Given this change in demographics, a specialised residential unit for people living with intellectual disabilities and dementia has recently been developed at Rose Cottage at Hohepa. One of the changes for the residents in this unit is that they have often 'retired' from their regular organised meaningful occupation and may be attending group activities in the main Hohepa facility less often, leaving more unoccupied time. This emphasises the importance of enriching their home environment and better utilising their front-line care staff to support them to engage in meaningful occupation.

Meaningful activities help to provide pleasure and enjoyment, a sense of belonging to the world, autonomy, and identity and to maintain health and well-being amongst people with dementia (Phinney, Chaudhury, & O'Connor, 2007). They can help reduce anxiety and stress (Stuckey & Noble, 2010) and a mechanism for friendly interactions and social stimulation (Charalambous, 2014). Opportunities to choose and engage in individualised activities rather than generic group activities may help people to experience a sense of control and empowerment (Steele & Linsley, 2015; Charalambous, 2014).

There is an increasing body of evidence to suggest that there are particular benefits in using what is known as Life History Work for people living with dementia (Beasley, 2016). The collection of life history information including likes, dislikes, interests, and roles provides insight into the individual's unique identity (Burton, 2010; Downs, 2013), to help care staff see the individual person and not just their diagnosis of dementia (Egan et al, 2007; Yamagami et al, 2007). Care staff can use such knowledge to create individualised interventions that enhance a person's well-being (Fletcher and Eckberg, 2014).

The ability to engage in meaningful activities in care environments may be hampered by a lack of resources (Charalambous, 2014), mixed messages about the importance of interactions not related to basic cares and the scope of other roles (Nolan et al., 1995), and low confidence in how to best engage people living with dementia (Galvin et al, 2010). The provision of simple resources to support a variety of activities, within an "activity trolley", including life history books, may be one way to inspire and support meaningful activities.

The PIE (Person, Interaction, Environment) programme consists of an observational tool and a linked process for making improvements in the quality of communication and care offered to people with dementia (Bradford, 2013). This involves observations of care exploring the extent to which staff are considering what is known about the individual as a Person to personalise their care; the quality of Interactions with staff; and the impact of the immediate modifiable physical Environment or organisation of care. The process for making improvements involves observers reflecting on these findings and

giving feedback to staff. The care team then identifies what is working well and what is not working so well in terms of person-centred communication and care. Action plans are generated, including practical and achievable short-term actions and longer-term actions. The implementation of action plans and changes in practice is informed by further observations of care.

Aim: The aim of the present study is to document the impact of improved resources and education for enriched engagement in a group home using a structured feedback process. The hope is to observe an incremental improvement in the quality of communication and care offered to the people with Down syndrome living with dementia.

## **METHOD**

This descriptive study will take place in Rose Cottage at Hohepa. The process for making change will entail the PIE cyclical process of practice development. The main steps to be taken in the 'PIE programme' are:

- a) Introducing staff in the use of PIE as a tool for effecting practice change
- b) Use of the PIE tool for observing current house practices (baseline)
- c) Intervention: Introduction and education about the new resource. An activity trolley will be provided with physical resources, including life history books, and instructional "tip cards" to help staff and visitors to offer and share a range of activities with the residents. The props are designed to help stimulate a wide range of activities involving conversation, exercise, calming, personal meaning, and/or cognitive stimulation. Staff will take part in an education session to understand the importance of activities, familiarise themselves with the resources and how they can be effectively used, and gather tips and strategies for successful engagement for people with cognitive impairment.
- d) Use of the PIE tool for observing current house practices (first repeat)
- e) Reflection on the observation findings
- f) Structured action planning with team to effect change
- g) Implementing changes identified with team
- h) Use of the PIE tool for observing current house practices (second repeat)
- i) Reflection on the observation findings and another cycle of planning

The PIE tool observations will be conducted for at least two 2-hour periods for each phase. Staff will also complete questionnaires about their confidence in engaging in activities and their feelings about their role. The analysis for the PIE will primarily be qualitative, comparing the phases across individuals.

## **STUDENT ROLE**

A self-contained pilot study of the activity trolley will be conducted within the studentship time frame to investigate changes in staff behaviour and attitudes, and the impact on the individuals with dementia, their interactions with staff, and the environment. The student will have the opportunity to gain supported experience in structured observations, data entry and management, analysis, and interpretation. The student will also gain practical experience in conducting research in a health care setting including issues such as understanding privacy and maintaining confidentiality. The student's role will include:

1. Familiarisation with key work in the area
2. Conducting PIE observations
3. Involvement in initial educational and PIE feedback / planning sessions
4. Data input and management
5. Participation in the analysis and interpretation of results
6. Literature review
7. Contributing to the dissemination of results.

## **POSSIBLE IMPACT**

As we celebrate the increasing number of people with Downs syndrome living into middle and later life it is important to develop "dementia capable" housing and supports to maximise their opportunity to live as full and healthy a life as possible, including maintaining interests through a range of activities (Resources for Integrated Care, 2016). Despite this importance, little research has investigated how supported accommodation services such as group homes can adapt to the changing needs of people with Down syndrome who develop dementia (Icano et al., 2013). This small scale project investigates one possible way that living environments can be enriched.

## Administration Details

1. Is ethical approval required? Yes

If Yes: please circle or tick one of the following:

- a) Applied for (provide application #)
- b) Approved (attach a copy of the letter of approval from the ethics committee or application #)
- c)  To be done

2. Are you able to provide the funding for this project (ie. \$5,000 for the student, incidental expenses should be met from departmental or research funds) No

If Yes: Please provide name of the funder \_\_\_\_\_

If No: Please provide ideas of possible funding sources, including past funding agents and topics often associated with this research area, for the Research Office to contact.

Canterbury Health Care of the Elderly Trust, Alzheimers

If Yes: You will be sent a request for more information.

3. Medical Records or Decision Support accessed No

4. Health Connect South or other DHB records No

5. Signatures:

- I have read the 2017/2018 Summer Studentship programme handbook.
- I am prepared to supervise the project and will be available to the student during the studentship (including Christmas/New Year break if the student is working during this time).
- I agree to assume responsibility for the submission of the student's reports to the Research Office by the due date 29 January 2018.
- I agree that the project lay report may be available to local media for publicity purposes.

Signature of Project Supervisor(s)


Susan Gee

Tracey Hawkes

Matthew Croucher

Date:

21 June 2017





- I understand that I am responsible for hosting the Summer Student chosen for this project and will meet any costs incurred. I agree that incidental expenses will be met from departmental or research funds.

Signature of Head of Department:

Janice Lavelle



Date: 28 June 2017

Signature of Clinical Director:

Brian Deavoll



Date: 28 July 2017