



Dementia: Early Diagnosis and Intervention

Addressing the terms of reference point 4: how best to deliver awareness and communication on dementia and dementia related services into the community.

Background

Dementia is an increasing challenge for the Australian community. The aim of this submission is to provide the outline of an implementation project to assist those members of the community who deal with people with dementia on a daily basis but who presently have no access to training on the illness and its signs and symptoms.

This could include individual family members or carers, volunteers at community centres or aged care facilities, and emergency service workers such as SES, Fire Fighters, Ambulance and Police. These people are confronted with the challenges of dealing with people with dementia and supporting them on a daily basis yet most of them will never have received any dementia awareness training in order to better understand the individual and be able to care for them, often in challenging or in demanding situations.

Introduction

There are currently 200,000 dementia sufferers in Australia, and at least 2 people are required to care for each individual. Over 400,000 people in the Australian community are currently affected directly by dementia and many millions indirectly. There is currently no community based training program for general members of the public (non-health care workers) who are directly affected by dementia. The information in the public arena is fragmented and not up to date with current best practice in many cases. The number of dementia sufferers is expected to increase to more than 750,000 by 2050.

Providing free access to evidenced based best practice material is important for empowering clients with underpinning knowledge about the disease and how to manage it. In most cases the client would be seeking this information from their GP or allied health nurse. This submission proposes the project to be initiated at the frontline in care at the time that a diagnosis is provided to the clients and at the same time providing free access to the correct information and education by way of frontline dementia learning and networking centre.

Outline

Frontline Care Solutions has developed a five module online training package designed to increase the understanding of dementia. The course is currently used by a number of our clients in the aged care sector.

This project ambitiously seeks to cost effectively train 55,000 carers from the general public over a 4 year period, starting with 10,000 trainees in the first year and increasing in years 3 and 4 up to 20,000 trainees in the fourth year. This represents a significant percentage of current non-health care carers.

As dementia is a complex and dynamic presentation for each individual sufferer, it comes with dramatic and significant change that it's confronting and challenging for both patient and carer. The education and communication needs must keep people informed and up to date.

Dementia sufferers display behaviours that can be very challenging for the carer or other individuals who need to deal with them. Behaviours can range from agitated and confused to uncooperative or aggressive. Carers sometimes mistake other signs and symptoms of disease, illness or infection for dementia and without adequate underpinning knowledge they often feel overwhelmed and out of their depth.

The online training delivered under this project would address these key aspects of caring for people with dementia by:

- supporting the needs of unpaid carers in dealing with people with dementia;
- enabling learners to identify specific signs and symptoms that can be present;

- provide underpinning knowledge to complex language and terms of reference;
- allows learners to reflect on the care they provide or the interaction they have with dementia sufferers; and
- Providing learners with activities and simulations that teach empathy and understanding for the person with dementia.

The primary benefit of online training delivery is that the same level of training can be provided to anyone with an internet connection, regardless of location. This is particularly important in a country such as Australia. As an **example** of the demographics, Queensland has been used to demonstrate the dispersed and diverse nature of the potential learner base.

Queensland is highly decentralised, geographically dispersed with significant demographic differences across and within all planning regions. Frontline Care Solutions is proposing to implement a blended on-line delivery framework that will ensure a consistently high level of training delivery across all planning regions in Queensland and the rest of Australia with augmented support for regions where particular needs such as Language Literacy and Numeracy (LLN) or culturally appropriate delivery and barriers to learning exist.

This means that carers in Blackall or Winton will receive the same high quality content and ongoing support as carers in Brisbane or the Gold Coast despite the geographical, cultural and service delivery differences. FCS is not proposing to exclude any areas from any of the planning regions based on the fact that the majority of remote areas have internet access, computer facilities in local libraries, community centres or community education centres. This model also takes in the needs of workers delivering community care who do not necessarily have a day-to-day workplace to attend.

Data

All data incorporated into the table below is taken from 2009 DoHA Aged Care Statistics

This is an abbreviated table only showing 7 out of 16 regions in Queensland representative of the demographics as an example to the national roll out proposal on this project.

Planning Region	Differences in Demographics, Remoteness & Flexibility
North Brisbane	Major City (MC). 12% of the total population are from Non-English Speaking Background (NESB) and 1% is Indigenous. 13% of the 70+ age group identify as NESB and 0.2% is Indigenous. No significant differences across suburbs. Blended LLN support is anticipated
Darling Downs	IR, IRA, OR, OR Australia (ORA), Remote (R). Very large and diverse region, larger regional centres (Toowoomba, Warwick) and small remote Indigenous communities. 4% of total population are NESB and 3% are Indigenous. 5% of the 70+ age group identify as NESB and 0.5% is Indigenous.
Far North	OR, ORA, R, R Australia (RA), VR, VRA. Diverse region comprising Indigenous communities (Arakun) and major regional centres (Cairns). Blended LLN and cultural support is anticipated as 9% of total population are NESB and 15% are Indigenous. 19% of the 70+ age group identify as NESB and 4.6% are Indigenous. 10 Indigenous specific providers.
Mackay	IR, IRA, ORA, R. Centred mainly in Mackay and North to Whitsundays, with main populations in regional centre. Blended LLN and cultural support is anticipated as 4% of total population are NESB and 4% are Indigenous. 7% of the 70+ age group identify as NESB and 0.9% is Indigenous. 2 Indigenous specific providers
North West	R, VR. Very remote region with relatively small population centres and vast distances between centres. Mt Isa is the major regional centre and blended LLN and cultural support is anticipated with Indigenous people comprising 28% of the total population. 3 Indigenous specific providers
South Coast	MC, MCA. Gold Coast region and major urban centre. Blended LLN and cultural support is anticipated as 11% of total population are NESB and 1% is Indigenous. 14% of the 70+ age group identify as NESB and 0.1% is Indigenous. 1 Indigenous specific provider.
Wide Bay	IR, IRA, OR, ORA. Diverse region comprising significant population centres such as Bundaberg and Hervey Bay smaller regional centres and Indigenous communities such as Cherbourg. 4% NESB and 4% Indigenous

Major differences between regions include significant distances between population centres in much of the state which provides different challenges to the provision of community care than in major regional or urban centres. This is the case both between and within planning regions.

Project

Frontline Care Solutions (FCS) (www.frontlinecaresolutions.com) proposes a national blended e-learning approach to the delivery of Dementia Care Training to those that are not currently provided with education. This proposal covers all planning regions in all states and territories and can be utilised to meet the learning support needs of unpaid carers, family members and emergency service personnel who do not have access to adequate information on dealing with people with dementia.

Family and domestic pressures and the very low rates of carer payments reduce the ability of most carers to personally fund their learning and attend training in their own time. Added to this are the cultural and LLN barriers of indigenous carers, people from Culturally and Linguistically Diverse (CALD) backgrounds and the barriers of regional remote workers who have extremely limited access to training opportunities.

Family members of persons living and suffering with the signs and symptoms of dementia find it difficult to both afford and attend formal training courses. They often receive confusing information and have difficulty in accessing the services being offered.

This project proposal directly addresses these issues by providing a flexible training framework and platform that:

- requires little or no disruption to daily care schedules;
- is highly engaging, intuitive and flexible for learners enabling them to complete the training at their own pace and at convenient times;
- provides audio, text and interactivity to assist people with LLN or other barriers to training;
- provides constant support through on-line carer networks;
- enables participants to view lessons or teaching points multiple times.

Participants will have access to the platform for continuous refreshing of knowledge and future access to new information and materials during the time that they care for and support a dementia sufferer.

Output	Project Outcomes	Project Outcome Measure	Program Outcome
Building a specific gateway for entry to the Funded learning portal	A specific gateway entry portal that contains the dementia suite of learning for the individual learner	The portal will matrix the usage and numbers of participants by use of an administration system and learning management system in the back of the portal	One access point for the funded learning in dementia training

Instructional Module: How to use the course	Users will gain the understanding of how to engage the portal and utilise the materials	The LMS will track the usage and the 24 hr support system	Participants are confident in using the learning materials
Module 1: <i>Understanding Dementia 1 - An Introduction</i> This module will give carers an introduction to some of the basics of dementia. The module will provide an understanding of dementia, explain the difference between confusion and dementia, the types of dementia and some of its causes, and go through the different stages of dementia.	At the conclusion of the dementia care courses, the learner should have: • Knowledge of the affects of dementia • An understanding of the principles of person centred care • A practical understanding of the different approaches and techniques to employ when working with those affected by dementia • An awareness of how to manage their behaviour to positively impact on those affected by dementia • An understanding of the boundaries and rights when working with those affected by dementia	The LMS will track the usage and the 24 hr support system	The courses cover the following topics: • An introduction to caring for those affected by dementia • What dementia is • Types and causes of dementia • Conditions that often accompany dementia • The different stages of dementia
Module 2: <i>Understanding Dementia 2 - Person Centred Care</i> This course is designed to introduce the concept of person centred care. It describes Maslow's Hierarchy of Needs, 'well-being' versus 'ill-being', Malignant Social Psychology and 'well-being' keys.	At the conclusion of the dementia care courses, the learner should have: • Knowledge of the affects of dementia • An understanding of the principles of person centred care • A practical understanding of the different approaches and techniques to employ when working with those affected by dementia • An awareness of how to manage their behaviour to positively impact on those affected by dementia • An understanding of the boundaries and rights when working with those affected by dementia	The LMS will track the usage and the 24 hr support system	The courses cover the following topics: • Maslow's hierarchy of needs • Well being versus ill being • The impact of carer behaviour • Increasing well being
Module 3: <i>Understanding Dementia 3 - Communication Skills</i> This course is designed to introduce you to communication skills. It describes the difference between verbal and non-verbal communication, active listening, the value of touching and the use of metaphors and symbols by people	At the conclusion of the dementia care courses, the learner should have: • Knowledge of the affects of dementia • An understanding of the principles of person centred care • A practical understanding of the different approaches and techniques to employ when working with those affected by dementia • An awareness of how to manage their behaviour to positively impact on those affected by dementia • An understanding of the	The LMS will track the usage and the 24 hr support system	The courses cover the following topics: • The impact of positive and negative communication • The use of voice • Effective listening • Use of metaphors and symbols • Empathy

with dementia to communicate.	boundaries and rights when working with those affected by dementia		
Module 4: <i>Understanding Dementia 4 - Activities and Occupation</i> This course covers: the building blocks of care, identify and biography, importance of culture, comfort and attachment, autonomy and agency, risks and rights, and activities and occupation.	At the conclusion of the dementia care courses, the learner should have: • Knowledge of the affects of dementia • An understanding of the principles of person centred care • A practical understanding of the different approaches and techniques to employ when working with those affected by dementia • An awareness of how to manage their behaviour to positively impact on those affected by dementia • An understanding of the boundaries and rights when working with those affected by dementia	The LMS will track the usage and the 24 hr support system	The courses cover the following topics: • The building blocks of care • Identity and biography • Importance of culture • Comfort and attachment • Autonomy and agency • Risks and rights • Activities and occupation
Module 5: <i>Understanding Dementia 5 - Understanding Challenging Behaviour</i> This course is designed to help you to understand that behaviour is a form of communication. Learning to deal appropriately with difficult behaviour is not easy, but can be achieved. Remember happy people do not indulge in behaviour we find challenging.	At the conclusion of the dementia care courses, the learner should have: • Knowledge of the affects of dementia • An understanding of the principles of person centred care • A practical understanding of the different approaches and techniques to employ when working with those affected by dementia • An awareness of how to manage their behaviour to positively impact on those affected by dementia • An understanding of the boundaries and rights when working with those affected by dementia	The LMS will track the usage and the 24 hr support system	The courses cover the following topics: • An introduction to challenging behaviour • Factors underlying challenging behaviour • The ABC approach • The carer's role in challenging behaviour

Dementia presents as a group of signs and symptoms which are different for each individual. It is this individual affect that the dementia has that is of significance to the supportive family and carers. Early diagnosis is important to the individual client of the GP and also their support networks. Learning and development increases and empowers the people who care for the sufferers of dementia and provides strength and trust in the bonds that we create in care giving.

It would be a great benefit to be able to provide the correct training and education for the community that is dealing with the frontline care of these Australians in need. As the epidemiology increases and the number of sufferers increase, so too will the need to provide information and communication to increase the awareness and support the community.

Kind Regards



Drew Dwyer BASS, BSN, MClinSc, MRCNA, QMACA, CFJBI

Principal Consultant Gerontology

Phone: 07 5351 1188

Fax: 07 5351 1444

Website: www.frontlinecaresolutions.com

Address: PO Box 1088 Coolumb Beach, QLD, 4573

