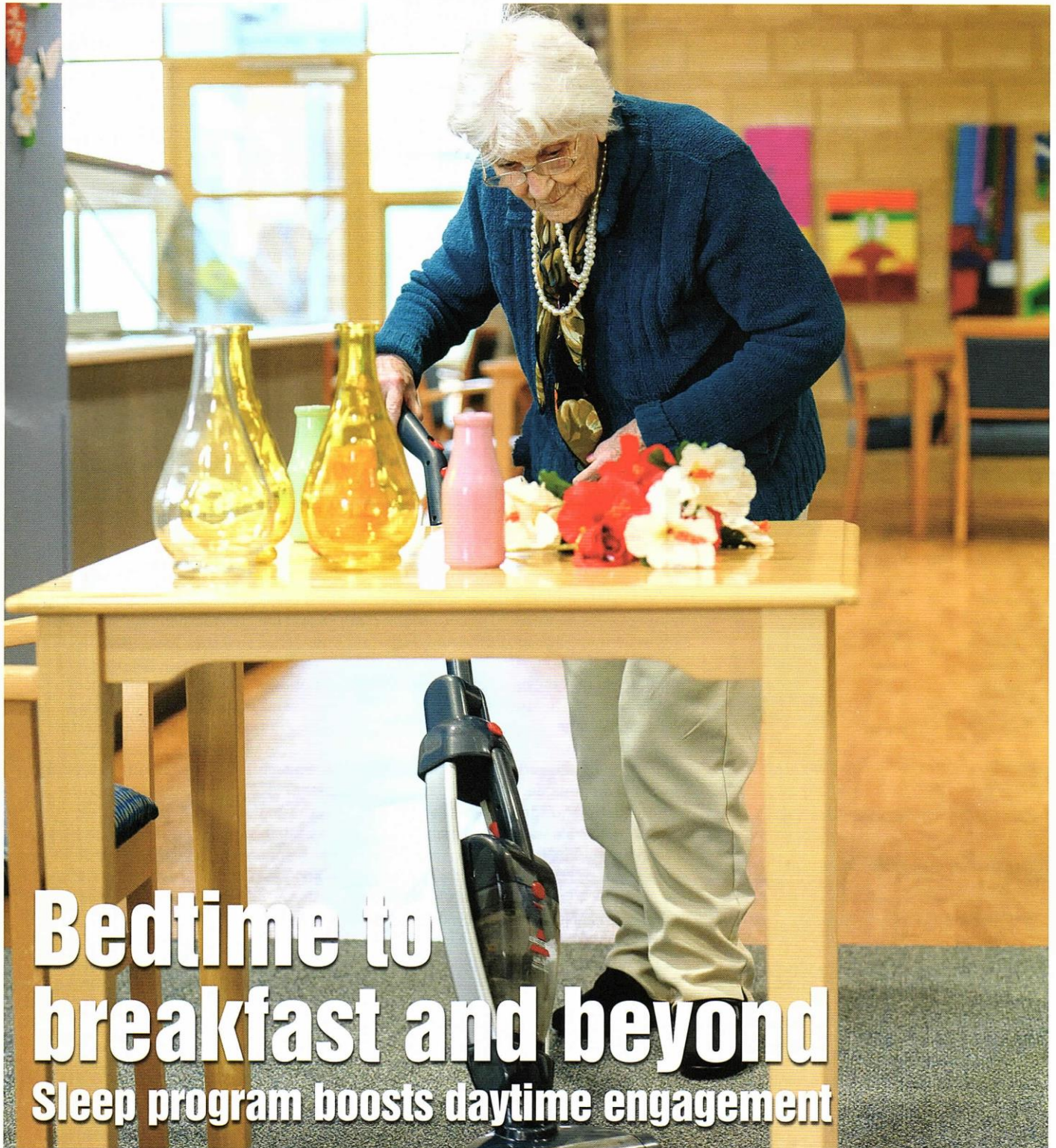


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For all who work with people with dementia

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Bedtime to breakfast and beyond

Sleep program boosts daytime engagement

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A tale from a dementia champion

The number of Australians living with dementia is increasing, and yet awareness and understanding about dementia is still alarmingly low among the general public (Dementia Australia 2017).

Most Australians don't know what dementia is. Few understand that dementia is not a natural part of ageing (Millard & Baune 2009). Unfortunately, this also includes some working in the aged care and medical communities where research has identified knowledge deficits (Robinson *et al* 2014).

I have also discovered there is resistance and barriers to dementia awareness and education in the community. These include traditional values and cultural beliefs about dementia; time constraints to attend education; and a fear of discussing dementia because of stigma, which is often reinforced by negative media stereotypes.

Local and international studies have identified that community misunderstanding about dementia results in significant levels of distress, rejection and social isolation for people with dementia and their caregivers (O'Sullivan *et al* 2014). A community that is not dementia-aware is less empathic to people with dementia (ADI 2012).

It is vital that we engage the general population to inform and transform their attitudes towards dementia. With this aim, during 2017 I launched and hosted a series of free public dementia education sessions in the Ku-ring-gai area of Sydney, NSW.

From a small start, these sessions have grown in reputation to the point where there is a recognisable change in community dementia awareness. As a direct result of this education, several local businesses and social groups, such as cafes, supermarkets and churches, have changed their



Tim England shares his experiences of creating a grassroots education campaign to transform community attitudes towards dementia

attitudes and beliefs about dementia and now promote dementia-friendly settings.

Background

After years working in the corporate sector and following a family illness, in 2010 I retrained to be an aged care worker. I gained the required qualifications quickly and began working with people with dementia living in the community. In late 2013, and while working full-time, I commenced a Bachelor of Dementia Care at the University of Tasmania. I graduated in late 2016 and consider myself a dementia champion.

In 2015/16 I looked at what I could do for my local community, Ku-ring-gai, in terms of dementia awareness. I found that there was no effective public dementia education within the Ku-ring-gai region of 120,000 residents. What was available was not comprehensive. Leaflets containing out-of-date information were available at community libraries, neighbourhood centres, council chambers, and through some doctors' surgeries.

There was little information about supportive strategies for people with dementia and

family caregivers, and nothing about preventing dementia. There was a clear need for uncomplicated educational sessions for the public if awareness and understanding about dementia was to improve.

In 2016 I completed a pilot program to test the need for a dementia education program that would be suitable for my local community. During the year I presented a short information session on dementia to 595 people from 17 community groups. The content was based on the latest evidence from Dementia Australia and the University of Tasmania's Wicking Dementia Research and Education Centre.

At each event participants were invited to complete a self-administered measure of dementia knowledge – the Dementia Knowledge Assessment Tool Version Two (DKAT2) (Toye *et al* 2013) – pre and post-presentation, as well as an audience feedback form to determine satisfaction with the presentation and areas for improvement. Over 90% of DKAT2 and feedback forms were completed and returned. I used the data collected in this pilot project to design the 'FACTS About Dementia' (FAD) program.

The 'FACTS About Dementia' (FAD) program

With the support of a \$2500 council grant that I acquired with the help of my local Rotary Club of St Ives, NSW, I presented a series of free public FAD sessions between March and September 2017. Each session ran for 60 minutes and was held at a suitable venue, including meeting and corporate training rooms, and community halls.

I encouraged audience involvement, used simple, non-technical language and allowed time for audience questions and open discussion. Each session covered what dementia is and (equally important) what dementia is not, prevention, and the simple steps that individuals can take to help create a dementia-friendly community. All participants received an information pack to take home.

Although the subject matter was confronting, feedback from attendees indicates that these FAD sessions were very beneficial. Before the sessions most had little knowledge about dementia. They did not know that dementia is not a normal part of ageing, that declining memory is only one symptom of dementia, that changing environments can have a negative impact on people with dementia, and that there is currently no cure.

Testimonies suggest that many attendees now have a greater understanding of the difficult challenges that



The author, Tim England (centre) during a FACTS About Dementia presentation for retirement village residents in Sydney



Tim England (right) with Probus Club members attending his FACTS About Dementia presentation

someone with dementia experiences daily, such as navigating their environment and communication. In particular, most attendees said they now understand the steps that can be taken to support the family carer.

Follow-up investigations suggest that many also now feel confident to assist people living with dementia in their community. As a result, Ku-ring-gai now has a new dementia-friendly café, the local Men's Shed welcomes members with dementia, and a local IGA supermarket has become a dementia-friendly business, with staff members attending FAD sessions and individual coaching sessions to help with communication techniques.

St Swithun's Anglican Church at Pymble has also modified and enhanced its monthly dementia-friendly church service, based on information from the FAD program. St Swithun's offers a streamlined one-hour Holy Communion service every second Thursday of the month for people with dementia and their carers. The first half hour is spent having morning tea and a chat, allowing people to relax and settle into their surroundings, followed by a condensed service with just two hymns, the Lord's Prayer and a shortened version of communion.

Results of the FAD program

As of November 2017 I have presented 32 FAD sessions to a total of 831 people. Participants have included people living with dementia, family carers, local political

and business leaders, registered nurses and doctors, university researchers, managers from retirement villages and local aged care facilities, and the general public.

Challenges

Despite the success of the FAD sessions, I did encounter, and still do, barriers that could derail the program. Some within the aged care sector simply dismissed it, possibly due to clinician bias or traditional beliefs. Encouragingly, I have hosted FAD sessions for staff at a few local aged care service providers, care facilities and retirement villages. At times these sessions were modified to address the specific knowledge gaps and language needs for each setting. I plan to continue these tailored sessions.

Local small businesses present their own challenges. For many business owners and staff, simply finding time to attend a FAD session was difficult. The solution was simple – I hosted sessions at their business premises after hours.

Marketing the FAD sessions was also a challenge. With a limited budget, I relied upon 'guerilla marketing' techniques: advertising strategies designed for businesses to promote their products or services in unconventional ways with little budget. This included: colourful leaflet drops, street banners and media releases about upcoming FAD sessions; car signage; and being a guest speaker at bowling clubs, tennis clubs, retirement villages, etc. I accepted the necessity to be the face of the project and continually sell the concept. This, coupled with the kind support of Rotary volunteers, engaging with community radio, and word-of-mouth promotions saw an increase in participants.

Funding

Aligning with the Rotary Club of St Ives and Ku-ring-gai Council was an excellent start.

Approaching community groups was also successful. I created a funding page on 'GoFundMe', and worked with an organisation called Comedy For A Cause, professionals in fundraising for community groups. I also monitored the availability of grants via the online site GrantGuru. A combination of these approaches has meant that funds have trickled in.

Buoyed by recent successes and encouraged by others, I plan to continue these public dementia education sessions. A small amount of additional funding is now available that guarantees sessions can continue for the next few months at least.

Conclusion

Dementia is a challenging topic for the general public to discuss and is often avoided. However, I keep reminding myself that avoiding the subject does not support those touched by dementia (Millard & Baune 2009). This is my motivation to continue to speak publicly about dementia.

I have two current goals: to reach 1000 local residents through free FAD sessions between now and 30 June 2018, and to inspire others to increase dementia awareness in their local community. To get this done requires passion, patience and persistence.

This has been a very personal journey. I think that public attitudes towards dementia can be transformed through education. As more families are touched by dementia, greater community awareness and understanding of dementia is required. My story is but one story. I have shared it with you in the hope that you are inspired to make a difference in your community too. ■

■ Tim England is a dementia care specialist, educator, consultant and advanced care planner, based in Sydney, NSW. For more information about the FACTS About Dementia (FAD) program contact Tim via his website www.dementiachampion.com or phone 0406 764 340.

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