

Institution: Cardiff University		
Unit of Assessment: English Language and Literature (27)		
Title of case study: Improving dementia communication for practitioners, carers, and people with dementia in the UK and internationally		
Period when the underpinning research was undertaken: 2008 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Alison Wray	Role(s) (e.g. job title): Professor	Period(s) employed by submitting HEI: 01/08/1999 – present
Period when the claimed impact occurred: 2016 – 2020		
Is this case study continued from a case study submitted in 2014? No		
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>Poor communication can cause confusion, frustration, stress and withdrawal in people living with dementia, as well as their families and professional carers. Better ways to address these communication challenges are long overdue. Wray's principles for effective practices, based on her new conceptualisations of what happens at the interface of social interaction and acquired cognitive disability, were used in workshops, animated films and new training materials. Through her work with dementia support organisations and other professional groups in the UK, USA, Australia and New Zealand, Wray's research changed dementia communication practices for professional and family carers, as well as a broader range of healthcare and allied support staff.</p>		
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>Around 50 million people worldwide have dementia, with that figure projected (by the WHO) to rise to 152 million by 2050. Since 2008, Wray has undertaken critical comparative research at the interface of linguistic, neuroscientific, communicative, cognitive and social theory. This multidisciplinary approach makes it possible to conceptualise the full picture of what happens to communication when someone is living with dementia. She has demonstrated how well-intentioned changes to communicative practices can have unintended consequences, leaving people who live with dementia (PwDs) and their carers/family feeling confused, frustrated, undermined and guilty. The research blends critically engaged theoretical evaluations of claims across disciplines with direct insights from Wray's own observational data on communication by, and with, PwDs, and with input from a range of stakeholder groups such as care providers.</p> <p>Four of Wray's articles [3.1, 3.2, 3.3, 3.4] explore particular aspects of PwDs' communication challenges, and the most extensive treatment of her ideas, centred on her <i>Communicative Impact</i> model, is found in her monograph [3.5]. The back cover quotes Prof. Robert Schrauf of Penn State University describing the book as "<i>an intellectual tour-de-force</i>" and "<i>an act of compassion</i>". The key claims in her work include:</p> <ol style="list-style-type: none"> 1) Dementia undermines social interaction by disrupting people's shared knowledge and assumptions. PwDs and their family/carers easily become anxious when unable to anticipate each other's knowledge, feelings and actions. Responding negatively (e.g. contradicting or getting angry) may strain relationships. Changing the patterns of responses between PwDs and their family/carers requires self-awareness and insights into the dynamics of communication [3.2, 3.3]. 2) It is often difficult to distinguish the effects of PwDs' impaired communicative and cognitive abilities from strategies used to compensate for them, and from instances of deliberate choices. For instance, does saying 'Happy Christmas' on someone's birthday indicate a misreading of the occasion, the mis-selection of a word, an attempt to use an inspired guess to disguise being unsure what is happening, or a joke? Not knowing which explanation applies can create embarrassing and perplexing ambiguities, which Wray terms awkward pragmatic gaps [3.3, 3.5]. Understanding their nature and causes can relieve carers of the unnecessary burden of trying to resolve these ambiguities. 		

- 3) **To remain empathetic and sustain realistic expectations, carers must balance two perspectives: seeing PwDs as essentially like themselves (different only in *degree*), versus seeing them as fundamentally different from them in *kind*.** The tension between these perspectives is most extreme in the *carers' paradox* [3.2]. Here, the *degree* perspective supports empathy, but also makes carers emotionally vulnerable to PwDs' (unintentionally) hurtful and unexpected behaviours. Conversely, excusing PwDs because they are different in *kind* creates the risk of dehumanisation [3.1, 3.3, 3.5]. Recognising this paradox can encourage carers to persist with empathetic caring [3.6].
- 4) **To complement the existing concepts of *brain reserve* and *cognitive reserve*** (recognised attributes that protect people against developing dementia), **Wray conceptualises two more 'reserves'** that shape people's response to dementia [3.5]. ***Social reserve*** is the level of practical resilience people have to living with dementia or caring for someone with dementia, as determined by (a) the healthcare and wider infrastructure they can access, (b) the prevailing cultural attitudes/practices (in part shaped by and reflected in media and policy discourse), and (c) the level of social credibility they are given. ***Emotional reserve*** is the capacity to cope with the challenging situations that dementia creates. It derives from inherent traits (e.g. emotional intelligence) and daily experiences. Low social reserve and/or emotional reserve will exacerbate the expression of underlying dementia symptoms (e.g. via increased depression, frustration and isolation), while high levels enable people to live well with dementia, and their carers to feel positive and fulfilled. Drawing carers' attention to how social and emotional reserve affect a person's experience of dementia gives them greater capacity to build and sustain these reserves in the PwDs and in themselves [3.6].
- 5) **Additional complex communication issues arise when PwDs and carers are not fluent speakers of the same language** [3.4, G3.1]. Wray has contributed to the sensitive discussion around the use of immigrant workers in dementia care (and the care of speakers of other languages living with dementia), by showing where the legitimate boundaries of good practice lie, and what is required to support second language speakers in the dementia care context.

3. References to the research (indicative maximum of six references)

[3.1] Wray, A. (2011). Formulaic language as a barrier to effective communication with people with Alzheimer's disease. *Canadian Modern Languages Review*, 67(4), pp.429-458. DOI: 10.3138/cmlr.67.4.429

[3.2] Wray, A. (2013). Mislaying compassion: linguistic triggers of inadequate caregiving. In Davis, B. & Guendouzi, J. (eds), *Pragmatics in Dementia Discourse*. Newcastle-Upon-Tyne: Cambridge Scholars, pp.117-45. Available from HEI on request.

[3.3] Wray, A. (2016). Mechanisms of conflict and aggression in the dementia context. *Journal of Language Aggression and Conflict*, 4:1, pp.114–140. DOI: 10.1075/jlac.4.1.05wra

[3.4] Wray, A. (2019). Multilingual dementia care: defining the limits of translanguaging. *Language Awareness* 28:3, pp.227-245. DOI: 10.1080/09658416.2019.1636801

[3.5] Wray A. (2020). *The Dynamics of Dementia Communication*. New York: Oxford University Press. Available in REF2.

[3.6] Morris, L., Mansell, W., Williamson, T., Wray, A., & McEvoy, P. (2018/2020). Communication Empowerment Framework: An integrative framework to support effective communication and interaction between carers and people living with dementia. *Dementia*, 19(6): pp.1739-1757. DOI: 10.1177/1471301218805329

Selected grants:

[G3.1] Alison Wray (UK Co-I), Norwegian Research Council funding for *Language and Communication in Multilingual Speakers with Dementia in Norway* (January 2016-December 2020). Cardiff share: £10,742, to research and produce two animated films [5.2c]

4. Details of the impact (indicative maximum 750 words)

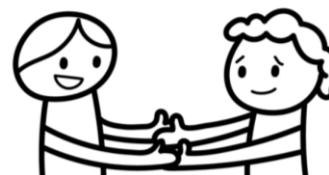
Wray's approach to explaining the broader effects of dementia on communication has generated new ideas that are positively supporting families, carers and healthcare professionals worldwide, both directly and via various training programmes. She was recognised for this work as one of three researchers shortlisted for Emerald Publishing's International Real Impact Awards 2019, *Mobilising Research into Action* category [5.1a].

4.1 Generation of new materials to increase understanding

Wray received ESRC Impact Acceleration funding (£9,000) to create two animated films based on her research [5.2a, b]. She researched and created a third film [5.2b] as part of a Norwegian Research Council project with the University of Oslo [G3.1]. Wray's scripts, drawing on her research findings and input from stakeholders, present usable messages for carers about the nature of communication in the dementia context, to support carers in improving their practices. Animated by David Hallangen, the films are voiced by Sir Tony Robinson:

- *Understanding the challenges of dementia communication* (2017, 16 mins) explains the causes of communication problems [5.2a, 3.1, 3.5].
- *Dementia: The 'communication disease'* (2018, 18 mins) offers practical ideas for improving communication [5.2b, 3.1, 3.5].
- *Dementia communication across language boundaries: Developing language awareness* (2020, 31 mins) explores the challenges for carers who do not have the same first language as the PwD and offers ideas for improving effective communication [3.4]. There is a version in Norwegian, with the content adapted for the Norwegian context (see [5.2c] below).

EMPOWERED
LESS ANXIOUS



Screenshot from *Understanding the Challenges of Dementia Communication* [5.1a], showing that carers can empower PwDs through better communication

Endorsed by the Alzheimer's Society in their Research Newsletter to 4,000 members [5.1b], the films had been viewed 11,206 [5.2a] and 6,832 [5.2b] times at 31/12/20. Feedback attests to their value in increasing understanding about dementia communication. For example: "a very accessible and powerful learning aid" [Head of Memory Care, Sunrise Senior Living, UK, 5.3]; "I appreciate the way your videos address the clinical realities of the disease...but in a way that is person-centred and focused on coping" [geriatric psychologist, USA, 5.4]. A Community Advisor for Alzheimer's New Zealand Northland stated: "Alison's two animations have been key to further my understanding of communicating with someone with dementia. They both provide practical useful strategies that carers can use in daily life" [5.5].

4.2 Improving practice and communication in dementia care

The films have been incorporated into training courses for family and professional carers, as well as for healthcare and allied professionals, in the UK, USA, Australia and New Zealand, with several organisations using them for both purposes.

a. Family and professional carers

Dementia carer training providers that have incorporated the animated films into their resources include: **UK:** Six Degrees' *EmPoWereD Conversations* (now part of AgeUK); Dementia Carers Count; Bluebird Care; Alzheimer's Society Central Lancashire; **USA:** VA Puget Sound Healthcare Washington State; **Australia:** Wesley Mission Queensland; **New Zealand:** Alzheimer's NZ Northland; Dementia Care NZ. For example:

- a geriatrician in Seattle highlighted how the videos "showed [family carers] how to break things down and what communication elements to prioritize" [5.4];

- the Education Coordinator of Dementia Care NZ said *“I think that the work you are doing is some of the most important I have encountered”*, and noted that he is using all three animations in the *Best Friends* training for professional carers [5.6];
- the Community Advisor for Alzheimer’s NZ Northland described how one of the animations [5.2A] *“provides practical steps of looking for the reason behind what [PwDs] are saying...this is invaluable to helping carers understand the ‘why’ behind those behaviours that challenge us. Which then helps carers to start to change their communication style”* [5.5]. She further stated that after viewing and discussing the animations *“I have seen some carers subsequently change their style of communication for the better, resulting in less stress, more love, and a better quality of life for both the carer and the person with dementia. For example, one carer said that after changing her communication style, for the first time in a very long time, her husband said to her ‘I love you’”* [5.5].

As part of Wray’s work with Wesley Mission Queensland (WMQ), an Australian residential care provider for >3,500 PwDs, she designed and presented 11 hours of tailored training workshops (2016-2018) for 12 senior HQ staff, 30 care managers and workplace coaches, 35 professional carers and 20 family members and PwDs. The organisation’s Workplace Diversity Project Manager stated: *“your training sessions for our staff were very helpful to them... You explained new ideas in a way they could understand and relate to their practices”* [5.7]. Wray participated in one WMQ training session developing the English language skills of 14 refugees aspiring to work in dementia care, who *“got a great deal from your visit”* [5.7]. This session helped to inspire the third animated film [5.2c] and a publication on multilingual dementia care [3.4]. The organisation continues to use the films in both carer and family training sessions, and in 2017 worked with Wray to develop further resources and toolkits for staff, families and volunteers on *“the right way to communicate with persons living with dementia”* [5.7].

b. Other healthcare and allied professionals

In addition to her work in Australia, Wray has worked directly with a range of healthcare and allied professionals in the UK to deepen their understanding of communicating with clients who have dementia. For example, she has twice presented her research at national staff training events (June 2016, November 2017, c.100 staff at each) for the UK residential care home chain Sunrise/Gracewell (47 homes, c.5,000 residents).

In a feedback survey of attendees at the event in 2017, 97% of respondents found Wray’s research valuable [5.3], and attendees said they would adapt their behaviour to change their language and be vigilant for possible breakdowns in communication, including: *“implementing phrases to let the client/family know that you understand”*, *“answering the unasked questions”*, and *“being aware of concerns that the family/client have but don’t say”* [5.3], all of which reflect the content of Wray’s research. A senior director for UK Sunrise/Gracewell wrote that as a result of the training: *“the team were thinking about how they can adjust/flex the content and style of communication with families who may be, and often are, struggling with those suffering from memory loss”* [5.3].

On three occasions (2016-18), Wray presented her research as part of St Padarn’s Institute’s ‘Communicating in Healthcare’ sessions for trainee multi-faith hospital chaplains from across the UK (c.50 participants). She was also the guest trainer of speech and language therapists at a meeting of the South West and Wales Dementia Clinical Excellence Network (March 2019) (c.25 participants). When asked what they would change as a result of attending this meeting, therapists noted they would *“think about what the person is actually trying to communicate”*; *“consider the importance of context in all types of assessment for people with dementia”*; *“review Alison Wray’s work and include it in my family education”* [5.8].

4.3 Six Degrees Social Enterprise training materials

Six Degrees is a UK Social Enterprise company that created *EmPoWereD Conversations* (EC), a communication-focussed workshop series for family and professional carers. From 2014, Six Degrees used Wray’s research and animations for EC workshop content, and in 2019 the workshops were shortlisted for *Best Training Initiative* in the UK’s Dementia Care Awards. In 2019-20, with support from ESRC IAA funding (£15,000), Wray collaborated with the EC team to develop two additional workshop sessions for EC (expanding the course from four to six sessions), drawing

directly on ideas in Wray's book [3.4]. EC reaches a client base across northern England, Wales and Scotland, with the first international course (Australia) commissioned in 2019 [5.9].

The Managing Director of Six Degrees commented: *"Alison's communicative impact model offers a clear frame of reference that can help family carers to think about the communicative challenges of dementia... This understanding helps carers to review their reactions to communicative challenges"* [5.9]. He also noted that the animated films contributed to *"significant improvements on measures of carer stress and the relational quality with the person who has dementia"* [5.9]. He reported one carer's account of how the EC training caused him to change his approach to communicating with his wife, who has dementia: *"as a result of the course he tried to change tack, by giving her an invitation to talk about her feelings...The couple felt calmer, emotionally close and supported by each other"* [5.9]. Feedback from the extended workshop provision in 2019-20 shows how the behaviour of attendees changed: *"I spend a lot more time with my mum perhaps just sitting quietly and stroking her back or something like that"; "I try to break things down, it's not good giving him three bits of information because only the first bit registered"; "more sensitivity has come in, because now we understand how she feels. Rather than just our frustration, it's also hers"* [5.10].

Every year, there are nearly 10 million new cases of dementia across the world. With the total number of people with dementia projected to treble over the next 30 years, supporting patients, carers and families through the associated communication challenges is crucial. Wray's research sheds light on what happens at the interface of communication and social interaction in the dementia context. By translating her findings into practical resources and training, she has improved the practice of key stakeholder groups navigating these challenges - including PwDs, healthcare professionals, families, charities, and care homes in the UK, the USA, Australia, and New Zealand - and ultimately improved their ability to communicate with PwDs.

5. Sources to corroborate the impact (indicative maximum of 10 references)

[5.1] Media sources: a. Emerald Real Impact Awards short list, 2019, b. Alzheimer's Society Research Newsletter December 2017

[5.2] Animations:

a. Animation: *Understanding the challenges of dementia communication* (2017, 16 minutes)

b. Animation: *Dementia: The 'communication disease'* (2018, 18 minutes)

c. Animation: *Dementia communication across language boundaries* (2020, 31 minutes)/ *Demens og kommunikasjon på tvers av språk: utvikling av språklig bevissthet* (2020, 35 minutes)

[5.3] Correspondence and feedback from Sunrise/Gracewell

[5.4] Email correspondence from a geriatric psychologist in Seattle, USA

[5.5] Testimonial from Alzheimer's NZ Northland Community Adviser

[5.6] Email correspondence from an Education Coordinator for Dementia Care New Zealand

[5.7] Testimonial and correspondence from the Workplace Diversity Officer and Dementia Framework Project Coordinator, Wesley Mission Queensland

[5.8] Feedback from South West and Wales Dementia Clinical Excellence Network (Speech & Language Therapists) after training presentation (March 2019)

[5.9] Testimonial from the Managing Director of Six Degrees Social Enterprise, Salford

[5.10] Report: 'A study of the impact of an expanded version of a communication-based course, "Empowered Conversations", for care partners of people living with dementia', Six Degrees Social Enterprise (May 2020)