

Australian Journal of DementiaCare Research Focus

This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

The Research Focus section of the *Australian Journal of Dementia Care* aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda. We would like to hear from you, specifically with:

- notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care;
- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

Communicating without speech

Adaptive Interaction (AI) is a non-verbal communication tool for people with dementia who can no longer speak. In this article, **Maggie Ellis** and **Arlene Astell** briefly describe the genesis of AI, its development over a number of years and how they see its future

Adaptive Interaction (AI) was born through synchronicity. A coffee-break conversation at a research meeting in 2002 between the Universities of St Andrews and Dundee planted the seeds that were to become AI.

Dr Suzanne Zeedyk (www.suzannezeedyk.com), a developmental psychologist from the University of Dundee, was drawing together researchers and practitioners from Scotland and Scandinavia to investigate using imitation as the basis for communication. This wide-ranging group worked with newborn infants, people with profound and multiple learning disabilities (PMLD), autism spectrum disorder (ASD), congenital deaf-blindness and severely neglected children.

Chatting in the coffee-break, Suzanne asked if imitation was used with people with dementia. At the time, we (Maggie and Arlene) were working on a project to support social interactions between people living with dementia and caregivers for which we were video-recording all interactions. Examining our recordings, we found examples of spontaneous imitation, for example harmonising movements when singing together, where people with



Dr Maggie Ellis initiating a connection with Vera during an Adaptive Interaction (AI) session. Photos: Brett Housego

dementia and caregivers 'connected'. Suzanne invited us to present these examples and our initial ideas about imitation in dementia at a small gathering entitled 'Promoting Social Interaction for Individuals with Profound Communication Needs', and to join the Scottish-Scandinavian Imitation Network (SSIN).

Between 2004 and 2007 the SSIN explored the role of imitation as the basis for communication for individuals who do not have speech. We were aware that a similar technique known as 'mirroring' (in which communication attempts are reflected back to the initiator) had previously

been used as a means of interacting/resolving conflict within this population (Feil 1993, Killick & Allan 2001, as cited in Henwood & Ellis 2015). However, this work lacks empirical evidence and differed from our approach in terms of theoretical origins. Our prior work was based on supporting conversation between people living with dementia and their caregivers and we were excited, but also apprehensive, about applying a non-verbal approach with individuals who had previously been able to speak. We have always been conscious that this was a major difference with the other populations in SSIN who have never learnt to

speak. However, we also knew from our work in care homes that many people with dementia reach a point where they can no longer use speech, which makes it difficult for them to be involved in social activities. As such, we joined SSIN with an open mind and optimism that the work being carried out with these other populations without speech would lead us to a communication tool for people with dementia who can no longer speak.

Intensive Interaction (II)

SSIN was built on imitation and the principles of Intensive Interaction (II) (Hewitt 1996; Nind 1996), a technique developed in the 1980s to facilitate communication between people with PMLD and their caregivers. People with PMLD experience extreme communication difficulties, with many never developing speech. However, all humans have the desire and urge to communicate, and individuals with PMLD are no exception. From this premise II seeks to uncover each individual's personal repertoire of communicative actions which provide the means to connect and interact with others (Caldwell & Horwood 2007). This starts with imitation.



Maggie and Jim: behaviour matching in action

Close behaviour-matching and imitation of sounds between parent and baby is the key to the development of speech in infants (Meltzoff & Moore 1983). II uses these fundamental interactions as a basis for connection and, although the structure and contents of these exchanges are non-verbal, it is difficult to argue that they are without meaning or emotion (Papousek 1995). It is important to note that these basic non-verbal communicative skills such as facial expressions, eye gaze and movements, are not limited to infants or to people with learning disabilities. All humans, regardless of age or cognitive status, use this type of communication every day but once we have speech we are mostly unaware of it. As such, we are not equating people without speech with infants, nor suggesting that they should be regarded as such.

Getting started: adapting II to dementia

Intrigued by the possibilities of using the principles of II with individuals with dementia who can no longer speak, we embarked on the first of our studies. This involved working with Jessie, a lady with dementia who could still produce words but not connected speech, to examine the role of imitation in her communication (Astell & Ellis 2006). Jessie's urge to communicate and participate in

social interactions through turn-taking, facial expressions and imitation was clear (Astell & Ellis 2006; Ellis 2009). She and her communication partner spontaneously imitated verbal and non-verbal behaviour to keep the interaction going over two sessions each lasting roughly 30 minutes.

Inspired by these initial findings, we were ready to take the next step of working with someone who no longer had any speech. Edie was an 80-year-old woman who had been resident in a care home for six years when we first met her. She was unable to walk or to take care of personal needs without assistance and to the untrained eye appeared to be completely non-communicative. However, observation over two days in her care environment revealed that Edie *did* make attempts to engage with others but that these were not recognised as such and so were largely ignored. For example, Edie made a very loud sound that most staff and residents found to be disturbing and as a consequence she was confined to her bedroom for most of the day.

Before commencing our work with Edie, we were extremely fortunate to spend two days with Phoebe Caldwell (www.phoebecaldwell.co.uk), another member of the SSIN, learning techniques for connecting with people who are non-verbal. Phoebe is a world-renowned expert in II and non-

verbal communication with people with PMLD and ASD and she shared her philosophy and practical skills with us. Imitation in the form of matched responsiveness is central to Phoebe's work and is the basis for connecting with people who are non-verbal (Caldwell 2005). Phoebe taught us how to identify communicative actions and reflect them back to the individual to make a connection. We found that by reflecting instead of ignoring Edie's distinctive sound we afforded her the opportunity to engage with another person using elements of her *own* language (Ellis & Astell 2008). Over multiple sessions Edie engaged with Maggie as her communication partner demonstrating turn-taking, sounds, movements, facial expressions, touch and perhaps most surprisingly, smiling and laughter (Ellis & Astell 2008).

Adaptive Interaction is born

An important aspect of II is that once a connection is made between a non-verbal individual and an interaction partner, this is built on over time into a communication model for each individual (Caldwell 2008). This demonstrates learning and expansion of non-verbal techniques into each person's unique communication style. As a progressive neurological disorder characterised by longitudinal impairment in memory and other cognitive processes, dementia is distinct

from other conditions where people never develop speech. If individuals with dementia reach the point of being non-verbal, they will have experienced pronounced changes in memory and other aspects of cognition. As such we could not presume that we could involve people with dementia who could no longer speak in learning activities to build up their communication skills. Rather, we decided to focus on connecting with the person, uncovering their individual communication repertoire and adapting our response to whatever they are doing at any given point. This approach requires the communication partner to meet the person where they are and to adapt their interaction accordingly. As such, we named this variant of II Adaptive Interaction (AI).

Building out from our initial success with Edie, we expanded AI through a small group study exploring the effectiveness of imitation in revealing individual communication repertoires (Ellis & Astell 2017). Working with this varied group of individuals confirmed the potential of AI for both connecting and communicating with people with dementia who can no longer use speech. Some of the group made no sounds at all but communicated through eye gaze, small movements and changes in their breathing (Ellis & Astell 2017). In all cases there was increased communication behaviour during AI sessions compared to usual (speech-



Maggie and Joan developing their connection during AI

based) interactions. The Table (right) illustrates AI behaviour modalities and some of the communicative behaviours used by individuals in the group.

AI training

All of this work was conducted in care homes, where there was initial scepticism followed by shock and realisation as we demonstrated that individuals who had been written off as communicators were still eager to participate in the social world. Our next step was to develop training for care staff which we initially tested in one care home where we had more families than staff willing to participate (Astell & Ellis 2011). Faced with anxiety and low expectations from those around us, we set about equipping four staff with the skills to identify and reciprocate communicative behaviours of four residents they were partnered with. This four-session program saw a major shift in both interactions between staff and residents and in staff attitudes towards both AI and the residents. Staff were extremely proud of their achievements when the results were presented to the residents' families and they had overcome their initial reluctance and embarrassment at using non-verbal communication.

From these initial pieces we consolidated our training model and started to raise awareness of how AI can benefit people with dementia who can no longer speak and those who care for them. For example, a training program run in Brighton in the UK showed that training caregivers with the skills to both recognise and use communicative action in the individuals for whom they care:

- Increased positive communication behaviours in people with dementia when compared to those in the control group.
- Decreased the amount of communicative behaviours that hinder and express displeasure in interactions for residents in the intervention home, while they remained stable in the control group.

Examples of Adaptive Interaction

The following table lists the communication modalities and some of the communicative behaviours used by people with dementia during Adaptive Interaction sessions conducted by the authors (Ellis & Astell 2017).

| Modality | Communicative behaviour |
|-------------------|--|
| Eye gaze | Looking at the other person Eyes closed Eyes closed tight |
| Sound | Coughing Yawning Speech sounds Clearing throat Heavy breathing Laughing High-pitched sound Growling sound Clicking tongue Sighing Singing Tutting |
| Movement | Pointing Nodding Shaking head Finger in/on mouth Looks at/plays with hands Lifting head off bed Shrugging shoulders Wringing hands Licking lips Head side to side Touching the other person Poking out tongue |
| Facial expression | Eyebrows raise Smile Frown Surprise Blowing kiss Winking |

Reference: Ellis M, Astell A (2017) Communicating with people living with dementia who are nonverbal: the creation of Adaptive Interaction. *PLOS ONE* 12(8): e0180395

• Improved Quality of Life for residents cared for by staff who were given training, while it remained stable in the control group (Dampney-Jay 2015).

We gave presentations at national and international conferences including in Germany, Norway, and the US and gradually received invitations to deliver training. To accommodate demand, we developed a one-day AI taster workshop to accompany our hands-on four-session training.

In addition to care homes, we have trained family caregivers and hospital nurses (Astell *et al* 2015) and in 2017 our book *Adaptive interaction and dementia: how to communicate without speech*, describing the principles and practice of AI, was published by Jessica Kingsley Publishers (see John Killick's review in Resources on p37). In 2017 we also established Astellis (www.astellis.co.uk) as an independent entity and have delivered our training programs in the UK, Bulgaria and Canada. We are able to deliver

the training anywhere in the world, including Australia.

AI and person-centred care

The question we are most commonly asked is "isn't imitation infantilising?" This concern reflects the power and reach of Kitwood's tenets of person-centred care in which he defined 17 'personal detractors' or negative modes of behaviour towards an individual with dementia (Kitwood 1990). Personal detractors take away from the personhood of the individual with dementia and 'infantilisation', where a caregiver treats a person with dementia as if they were a very young child, is one of these negative behaviours. Over the many years we have worked in this field we have witnessed infantilisation, along with other personal detractors, primarily when a caregiver did not know how to interact with a person with dementia and wanted to distance themselves from their apparent incompetence. In contrast, imitation as taught in AI is a tool for connecting with an individual, attuning ourselves to their communicative behaviours and following their lead to build up a meaningful interaction. AI respects the personhood of the individual with dementia and reflects Kitwood's observation that: "In the course of dementia a person will try to use whatever resources he or she still has available. If some of the more sophisticated means of action have dwindled away, it may be necessary to fall back on ways that are more basic, and more deeply learned; some of these were learned in early childhood" (Kitwood 1997 p75).

What have we learnt along the way?

AI started out as a research topic and our findings include that the urge to communicate is retained even when speech has gone, that AI can uncover the communication repertoire of people who cannot speak, and that interactions based on AI increase indicators of wellbeing such as smiling and laughter. Additionally, over the years we

have discovered a number of issues of relevance not just for AI but also for care of people with advanced dementia as a whole. Although AI is focused on creating connection above facilitating message-based communication, this aim does not necessarily preclude the exchange of more complex information. For example, an AI communication session may well illuminate the existence of pain or discomfort in a person with dementia. Such insight is likely to have implications for care provision.

First, when we train caregivers in AI, we initially ask them to engage with an individual with dementia as they 'normally' would. In this initial interaction, caregivers bring along a prop, typically food or drink. We realised quite quickly that this is because their normal interactions with non-verbal individuals take place during the course of routine care activities such as giving someone food or drink. They do not just have social interactions. Reassuringly, once caregivers have the opportunity to focus solely on communication and getting to know the individual, they find it increasingly easy to communicate with people with advanced dementia on their own terms.

Second, considering the questions about infantilisation, we initially wondered if discussion of the developmental underpinnings of AI might not sit well with our trainees. However, our research into this (article in preparation) has shown that it is most effective to face this theoretical point head on. Indeed, developmental theory is crucial for explaining AI and enabling caregivers to understand its basis.

Third, we have found that attitudes towards using the principles of II with people with dementia have changed markedly since we started our journey with AI. To begin with, care staff thought we were 'kidding ourselves', some family members thought it was 'pointless' and there was widespread scepticism. At the start of training, caregivers are

extremely self-conscious about being observed interacting and applying non-verbal means. However, once they are equipped to take the first steps, their whole focus shifts to the interaction and learning the language of their partner with dementia.

We believe for the most part that *witnessing* the impact of AI on people with advanced dementia and their caregivers changes people's perspectives. It would appear that the notion of using AI is more challenging than actually watching or participating in it. This perhaps seems counterintuitive as one might expect discussion of the approach to be less controversial than seeing it in action. However, we have consistently found that people develop a deeper understanding of AI and the reasons why it is important when they witness or take part in it as opposed to hearing or reading about it. We maintain that this change of heart occurs largely in response to the affective nature of taking part in AI rather than just watching video footage of it in action. This emotional quality is far easier to feel than to explain; a point often echoed by trainees.

Challenges of implementing AI

Sadly, the challenges of implementing AI in everyday

care are no different to any other person-centred intervention. Care facilities are short on time, money and often, knowledge of how to make life better for their staff and residents. In order to facilitate person-centredness in dementia care, we need to 'care' as much about people at the end of their lives as we do about those at the beginning. The blatant irony here is that AI is based on developmental psychology and our understanding of how infants learn to talk. As a society, we are extremely invested in how our infants develop and as such devote a significant amount of resources to facilitating this process. For under two-year-olds in nursery care, the recommended staff-infant ratio is one carer to three infants. There is no equivalent framework in place for dementia care facilities and as such this population typically receive care that is rushed, functional and perfunctory. We pay little heed to the psychosocial needs of people with dementia who can no longer speak. What's worse, we are often unaware that these individuals indeed *have* such requirements.

Going forward

We continue to research and advance knowledge about communication beyond speech. This includes looking for ways

to enhance caregivers' abilities to recognise communicative behaviour in people with dementia who cannot speak as well as exploring the impact of AI through physiological measures including salivary cortisol and oxytocin (the so-called 'love' or 'cuddle' hormone). We supervise students and deliver presentations and remain engaged in the II and dementia care communities. Interest in our training is growing, although we recognise the financial climate in both health and social care is challenging and likely to remain so. However, we remain optimistic that the synchronous coffee-break discussion in 2002 will continue to benefit people living with dementia who cannot speak long into the 2020s and beyond. ■

Resources

For information on Adaptive Interaction communication and training, visit the authors' website at www.astellis.co.uk/.

Their book, *Adaptive Interaction and dementia: how to communicate without speech* (Jessica Kingsley Publishers) (see p37, this issue), includes free downloadable resources available at: <http://bit.ly/jkp-AI>

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Nancy and Maggie forming a deep connection during AI

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Maggie and Vera laughing together during AI

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Research updates

Abnormal prescribing patterns

A new Australian study published this year in the *Journal of Pharmacy Practice and Research* has revealed that nursing home residents living with dementia are more likely to be prescribed medications for treatment of responsive behaviours, pain and urinary tract infections than those without dementia. The Flinders University study, working with the NHMRC Cognitive Decline Partnership Centre at the University of Sydney, investigated dispensing data from the individual pharmacy records of 541 residents at 17 Australian not-for-profit nursing homes; 348 (64.3%) had dementia and 193 did not have dementia. They found that a quarter of people with dementia living in nursing homes were prescribed the antipsychotic drug risperidone (suggesting this is likely to be overprescribed) while people with dementia were generally less likely to be given prescribed cardiovascular or respiratory treatments. Differences in over-prescription and under-prescription may reflect reduced awareness of, or ability to communicate, symptoms by those residents living with dementia, researchers at Flinders and Sydney University say. The paper, *Patterns of medication prescription by dementia diagnosis in Australian nursing home residents: a cross-sectional study*, is available at: <https://onlinelibrary.wiley.com/doi/10.1002/jppr.1457>

Drug trial discontinued

Pharmaceutical company Roche has discontinued early its phase III clinical trials of the potential Alzheimer's drug, crenezumab (referred to as CREAD 1 and CREAD 2), which was designed to treat people in the early stages of Alzheimer's disease. Sandra Horning, Roche's Chief Medical Officer and Head of Global Product Development, said that while the results were disappointing, they still contribute to an understanding of Alzheimer's disease. She said Roche remains committed to ongoing clinical studies in Alzheimer's disease, including phase III trials with gantenerumab, its phase II anti-tau trial

(TAURIEL), and its Alzheimer's Prevention Initiative (API) study of crenezumab in familial Alzheimer's disease.

Cognitive reserve and dementia

A new study published in *Neurology* has concluded that education does not play a role in when dementia starts or how fast it progresses. Rush University Medical Centre in Chicago conducted the study which investigated the contribution of education to cognitive reserve by analysing information from two long-term studies involving 2899 participants. Commenting on the findings, lead study author Dr Robert Wilson said, "It's possible that the contribution of education to cognitive reserve depends on other factors, such as life experiences or biological factors, but these results did not show a relationship between a higher level of education and a slower rate of decline of thinking and memory skills or a later onset of the accelerated decline that happens as dementia starts." The researchers did identify an association between having a higher level of education and higher thinking and memory skills at the start of the study, decades after formal education had ended.

Alcohol and dementia risk

A systematic scoping review has attempted to clarify the conflicting evidence about the relationship between alcohol and dementia risk – and concluded that reducing heavy alcohol use may be an effective dementia prevention strategy. It also says future studies need to address the limitations of the research to date. The review, published in *Alzheimer's Research and Therapy*, identified 28 systematic reviews published between 2000 and 2017. Light to moderate alcohol use in middle to late adulthood was associated with a decreased risk of cognitive impairment and dementia (causality could not be established). Heavy alcohol use was associated with changes in brain structures, cognitive impairments and an increased risk of all types of dementia.