


<b>Section A</b>		
<b>Institution:</b> University of St Andrews		
<b>Unit of Assessment:</b> UoA 04: Psychology, Psychiatry and Neuroscience		
<b>Title of case study:</b> Making communication possible for people with advanced dementia		
<b>Period when the underpinning research was undertaken:</b> 2006-31 December 2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Maggie Ellis	Senior Lecturer	01 October 2001 - present
Arlene Jean Astell	Senior Lecturer	01 October 2001 - 31 January 2013
<b>Period when the claimed impact occurred:</b> 2014-31 December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<b>Section B</b>		
<b>1. Summary of the impact</b>		
<p>50,000,000 people worldwide have dementia. In the advanced stages, the ability to speak and understand speech is often lost. Research by Ellis &amp; Astell has found that people with advanced dementia retain both the urge to interact and individual repertoires of nonverbal communicative capacities including sounds, movements, facial expressions and the ability to imitate. Adaptive Interaction is an approach building on these findings in which caregivers use residual communicative actions to re-engage individuals with advanced dementia. This has profound implications for the care of a population of individuals with advanced dementia who have until now, suffered severe social isolation. Specifically, the research has:</p> <ul style="list-style-type: none"> <li>• Changed care practices for those with advanced dementia through training of 261 carers across 10 care facilities in the UK and abroad.</li> <li>• Resulted in the Alzheimer's Society (UK) commissioning an Adaptive Interaction training course for volunteers as part of their communication learning pathway.</li> <li>• Changed dementia care in Scotland through inclusion in the Advanced Dementia Practice Model, the key guidelines for dementia practice produced by Alzheimer Scotland.</li> <li>• Changed public understanding of the communicative abilities of those with advanced dementia and the need for interventions like Adaptive Interaction to meet the need for social interaction in this population.</li> </ul>		
<b>2. Underpinning research</b>		
<p>Our lack of awareness of the communicative capacities of individuals with advanced dementia is detrimental to the wellbeing of those living with the condition, their professional carers, and family members. Individuals with advanced dementia become ignored and isolated, professional caregivers feel unable to communicate with those for whom they care, and family members feel disconnected from their loved ones. In 2006, Ellis &amp; Astell demonstrated that the desire to communicate and interact with others is present in people with advanced dementia, despite their lack of language and understanding of speech (R1). The problem is thus to find a way of communicating without speech. A solution to the problem is to adapt interpersonal interactions to utilise preserved repertoires of nonverbal behaviour and the capacity for imitation.</p> <p>Early work showed that imitation of nonverbal behaviour was effective for increasing communication in children with profound learning difficulties. This was called intensive interaction. Before 2006, the effectiveness of this imitative approach had not been explored with people with advanced dementia. Ellis noted that, for such people, the focus on behaviour had to be different to those with learning disabilities. For example, relationships with people with advanced dementia</p>		

are unlikely to develop over time owing to severe memory impairment. Ellis and Astell, therefore, adapted procedures to whatever behaviour the person was currently engaged in, hence the name of the approach 'Adaptive Interaction'. More recent and extensive research from 2017 indicated that this approach increased wellbeing and communication in people with advanced dementia. Notably, individuals with advanced dementia demonstrated higher frequency of smiling and imitation during sessions using Adaptive Interaction compared to more standard attempts at verbal interaction (R2). The research showed that, by identifying and responding to nonverbal communicative repertoires, caregivers and family members benefit from a previously unrealised method of interaction. Most importantly, those individuals with dementia can, once again, experience human connection.

Ellis & Astell went on to publish a book in 2017, aimed at public and professionals alike which is a guide to Adaptive Interaction explaining how to assess, access and utilise the communication repertoires of people with dementia who can no longer speak. The guide offers practical interventions for those who wish to interact with individuals with advanced dementia (R3). Ongoing research through recent collaboration with Dr Oggie Arandelovic, of the School of Computer Science University of St Andrews, has developed an automatic (artificial intelligence based) quantification of the degree of participant engagement in Adaptive Interaction sessions. This approach, based on computer vision and machine learning, has shown that the positive effects of Adaptive Interaction can be measured with an objective, unbiased approach (R4).

### 3. References to the research

The underpinning research was supported by peer-reviewed grants through Alzheimer Scotland, Alzheimer's Research UK and the Scottish Funding Council and has been published in peer-reviewed journals and conference presentations, as well as a book positively reviewed by leading professionals working for Alzheimer's organisation in Scotland and the UK including the Chief Executive of Alzheimer Scotland.

R1. Astell, A. J., & Ellis, M. P. (2006). The social function of imitation in severe dementia. *Infant and Child Development*, 15(3), 311-319. DOI: [10.1002/icd.455](https://doi.org/10.1002/icd.455)

R2. Ellis, M., & Astell, A. J. (2017). Communicating with people living with dementia who are nonverbal: the creation of Adaptive Interaction. *PLoS One*, 12(8), [e0180395]. DOI: [10.1371/journal.pone.0180395](https://doi.org/10.1371/journal.pone.0180395)

R3. Ellis, M., & Astell, A. (2017). *Adaptive interaction and dementia: how to communicate without speech*. London: Jessica Kingsley Publishers. ISBN: [9781785921971](https://www.isbn-international.org/product/9781785921971)

R4. Zhang, L., Dewar, S., Arandjelovic, O., Ellis, M. (2020). Quantification of Advanced Dementia Patients' Engagement in Therapeutic Sessions: An Automatic Video Based Approach using Computer Vision and Machine Learning. *42<sup>nd</sup> Annual International Conference of the IEEE Engineering in Medicine and Biology Society*. <https://ieeexplore.ieee.org/document/9176632>

### 4. Details of the impact

Ellis and Astell's research on Adaptive Interaction has affected practice in care for those with advanced dementia. It has changed practices within NHS, local authority and private care facilities, and been incorporated into the practice guidelines for advanced dementia and end of life care produced by Alzheimer Scotland. The research has changed public opinion about the communicative abilities of those with advanced dementia and had a profound effect not only on those living with advanced dementia but also their family members and carers.

#### **Context for impact: Lack of social support for advanced dementia**

At present, there is no cure for dementia and no effective treatments for the disorder once it has been diagnosed. In particular, very little specific care is aimed at those with advanced dementia as they are thought to be unable to communicate and have no chance of recovery. Ultimately, people with advanced dementia experience care that addresses only their physical needs, overlooking a significant unrealised need for social connection. Scottish Care estimates that between 12,000 and 15,000 people with advanced dementia are currently living in Scottish care

homes. Given that people can survive in this condition for many years, it is clear that there is an urgent need to provide specialised care and social support for people with advanced dementia and their families. Ellis and Astell's research on Adaptive Interaction addresses this need.

### **Changing practice in care facilities**

Adaptive Interaction is based on carers using the residual communicative abilities of those with advanced dementia who have lost the ability to speak. This includes imitation of vocalisations and movements. As such, this requires training and practice to help carers identify and imitate intentional communicative acts making Adaptive Interaction training time and resource consuming. Consequently, Ellis, Astell and collaborators have taken a "train the trainers" approach with two aims: firstly, to demonstrate the profound effect of Adaptive Interaction both on carers and those living with dementia in multiple care settings including the NHS, local authority and private care facilities (both in the UK and abroad); and secondly, through giving workshops to train carers in Adaptive Interaction to enable them to take the technique back to their care facility and teach other carers. Both of these aims have been achieved. Since 2013, the training has been given to 252 people (carers) from 10 care facilities, including NHS and private organisations across Scotland, the UK, and internationally. An example of how the training is then cascaded through organisations is given by Education Co-ordinator/Trainer at Salisbury NHS Foundation Trust who states *"All our dementia/delirium link role nurses and departmental staff are sent the [Adaptive Interaction] research video.... as a mandatory part of their training for the role. They have a responsibility to cascade information and access to training to all members of the team on their ward or department."* (S1). The effects of Adaptive Interaction have been shown to be transformative for carers and patients as detailed below.

Ellis and Astell's research shows the value of Adaptive Interaction to those living with advanced dementia (R1, R2). However, the success of Adaptive Interaction goes well beyond the effect on those individuals having a profound effect on carers and families. Firstly, it affects attitudes of carers trained in the workshops. Interviews and feedback following Adaptive Interaction training showed a change in care staff attitudes and behaviour towards individuals with advanced dementia. Changes included an increase in interpretation of behaviour as communicative in nature which is key as this provides positive feedback for the carers' efforts for further interaction (S2).

A carer from a Care Home in Glenrothes stated, *"I found that [Adaptive Interaction] AI brought something out of the clients that was hidden. Even if it was only blinking an eye, it was blinking an eye in response to something that we had done. Before, we wouldn't recognise it but with the AI training we realised that it was a response to us... Using this technique, I felt that I got something out of the residents that made my job easier."* (S2) These types of responses were common and following training at an NHS workshop in 2018 (NHS Salisbury) participants were asked after the event how confident they now felt communicating with someone with dementia and the mean response was 7.77 (median 8) on a scale from 1 (Not confident) to 9 (Very confident) (S3). Secondly, the changes in those living with dementia that result from Adaptive Interaction affect their families. The significance of the changes brought about by the adoption of Adaptive Interaction is evident in letters from the families of those with dementia. One family notes the effectiveness of Adaptive Interaction: *"I saw my mum smile, laugh and connect with Dr Ellis in a way I hadn't seen her do with anyone other than myself in years"*. (S4, p. 3) Another family member, using the technique with her mother, writes: *"I kissed her on her forehead and she opened her eyes, lifted my hand to her mouth and kissed it three or four times. My brother nearly fell off his chair"*. (S4, p. 2)



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These examples provide compelling evidence that practitioners and patient relatives' experience of communication is improved by Adaptive Interaction. Recent work in collaboration with Computer Scientists at the University of St Andrews validates this improvement by showing that an artificial

intelligence-based machine learning approach can detect improved non-verbal communication with 97% accuracy (R4). This provides an objective bias free measure of the improvement in communication following Adaptive Interaction training.

### **Alzheimer's Society commissions Adaptive Interaction masterclass**

In 2016, Astell and Ellis were commissioned by the Alzheimer's Society, the UK's leading dementia charity, to develop a one-day masterclass (training the professional trainers) in Adaptive Interaction as part of their communication learning pathway to be delivered by their most experienced lead trainers to those responsible for service delivery. Those trained are now delivering one-day regional courses for volunteers across the UK. The Organisational Development Manager of the Alzheimer's Society estimates the scope of the training to be '2000 paid workers and 6000 [people] volunteers' (S5). This commission resulted in the development of a dementia care training business 'Astellis' in 2017. The company delivered its first training programme in 2019 to NHS Speech and Language Therapists in Leeds. The company was recognised for demonstrating social impact by the Converge Impact Challenge which helps the most innovative and creative thinkers from academia to realise their entrepreneurial ambitions. Astellis was 1 of 5 finalists for their impact award in 2019 from a field of 44 companies.

### **Changes to Alzheimer care guidelines in Scotland**

Dr Ellis was included in the consultation process for the Advanced Dementia Practice Model, the guidelines for dementia practice from the national body, Alzheimer Scotland. As the CEO of Alzheimer Scotland explains, *"This important document provides the key to delivering people with advanced dementia and their families with the right to the best possible life and end of life care."* (S6). As a result of this consultation, Adaptive Interaction was included in the Advanced Dementia Practice Model from 2015 (S7; the Model cites an Adaptive Interaction practice handbook which itself cites R1). Alzheimer Scotland has wide reach with 66,800 people (subscribers), all of whom received a copy of the 2015 Model. This has produced sustained interest evidenced by 1,393 visits to the webpage since August 2019. The guide is used by Care Professionals to inform best practice. As an example, a Lecturer in Care at Dundee College said: *"I regularly use the Alzheimer Scotland Advanced Practice Model in my working life to maintain knowledge of standards of excellent practice.... Dr Ellis's contribution to advanced dementia care is changing how people with the condition are regarded for the better"* (S8). Care places a considerable strain on carers and family. While not eliminating Alzheimer's disease, Adaptive Interaction can provide human connection for those living with advanced dementia. As noted by the CEO of Scottish Care Ellis and Astell's research *"helps to build a bridge between our world of verbal communication and the world of individuals with dementia which is traditionally been a bridge that hasn't existed"* (S9). By supporting communication, Adaptive Interaction increases the wellbeing of those diagnosed (R1-R3) and the satisfaction of caregivers, including family (S2&S4). The Organisational Development manager of the Alzheimer's Society Manager writes, *"This has proven invaluable in providing people with advanced dementia, care staff and family members with the means of engaging in mutually meaningful interaction without the need for speech. Such interactions have a positive impact on the quality of life for all concerned."* (S5)

### **Changing public opinion of communicative abilities of those with advanced dementia**

A critical aspect of Adaptive Interaction is educating the public about the capabilities preserved in people with advanced dementia and their desire to communicate (despite loss of language production and comprehension). Ellis and Astell's work has changed public opinion through a variety of public engagement activities. These have included sustained engagement consisting of interviews on national media (STV news in 2014 (S10)) multiple public lectures each year since 2014 across Scotland and the UK, talks to carers' groups (National Dementia Carers Action Network, 2015) and keynote addresses to professionals (NHS Gloucester, NHS Salisbury, 2018). As an example, the Chief Executive of Alzheimer Scotland, who acted as Chair for a public lecture, notes that *"[he] was extremely well attended and received and drew much-needed public attention to the communicative issues faced by individuals with advanced dementia and their caregivers."* (S6). Further evidence of change in public opinion can be seen in the feedback to these events. Specific feedback demonstrating a change in opinion included surprise that *"advanced dementia patients are communicating! Important to communicate back"* and *"That any non-verbal behaviour is probably a means of communicating and that very disabled people's lives could be given some*

meaning". It was noted *"That I can communicate with someone with dementia. It is possible to 'reach them' if I take the time"*. Also, that *"Realising that apparently random acts may be an attempt at communication is a bit revolutionary for me"* (S3, selected quotes). Finally, the importance of Adaptive Interaction was noted, *"Basic human communication and the need is the last thing to go. Using Adaptive Interaction can maintain the sense of being alive for a person with dementia"* (S3). Further public engagement has been facilitated by Ellis and Astell's Adaptive Interaction research being featured prominently on the website of the Social Care Institute for Excellence (SCIE (S11)). The SCIE is an independent agency operating at both policy and practice levels to contribute to the development and implementation of better care, support and safeguarding at national and local levels. SCIE clients include care and health providers, local authorities, housing associations and government departments. Ellis's content on advanced dementia receives on average 1,000 views per month.

Ellis and Astell published a book, aimed at public and professionals alike which is a guide to Adaptive Interaction explaining how to assess the communication repertoires of people with dementia who can no longer speak. The book offers practical interventions for those who wish to interact with those with advanced dementia (R4). The book has received acclaim from relevant leading professionals including the Organisational Development Manager of the Alzheimer's Society (S12, p. 2) and the Chief Executive of Alzheimer Scotland who says: *"The text enhances our ability and skills in such a way as to ensure we treat the person living with dementia as an equal and valued citizen engaged with the world and people around them in a truly meaningful way."* (S12, p. 2).

In recognition of her work on Adaptive Interaction, Ellis was voted as one of the UK's top 100 Lifesavers as part of the MadeAtUni campaign in 2019. MadeAtUni is a new campaign from Universities UK to bring to life the impact of universities up and down the country on people, lives and communities (<https://madeatuni.org.uk/university-st-andrews/new-technique-help-dementia-patients-communicate>).

The Nation's Lifesavers are the top 100 individuals or groups based in universities across the country whose work is saving lives and making a life-changing difference to our health and wellbeing. This award serves to recognise the importance of Ellis' work on improving the lives of those with advanced dementia.



## 5. Sources to corroborate the impact

- S1: Letter from Education Co-ordinator/Trainer NHS Salisbury.
- S2: Quotes from Lomond Care Home Staff.
- S3: Feedback from NHS Salisbury workshop.
- S4. Letters from families using Adaptive Interaction.
- S5. Letter from Organisational Development Manager, Alzheimer's Society.
- S6. Letter of support from Chief Executive of Alzheimer Scotland.
- S7. Advanced dementia practice model: Alzheimer Scotland (see p.40 and p.50).
- S8. Letter of support from Lecturer in Care, Dundee & Angus College.
- S9. Letter of support from CEO of Scottish Care.
- S10. STV news interview (<https://www.youtube.com/watch?v=L6JmzNEQZjk>).
- S11. Social Care Institute for Excellence website.
- S12. Reviews of Adaptive Interaction and Dementia.