

BOOK REVIEW

Maggie Ellis & Arlene Astell. (2018). *Adaptive Interaction and Dementia: How to Communicate Without Speech*. London: Jessica Kingsley Publishers. ISBN 978-1-78592-179-1

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Introduction

Dementia is an umbrella term used to describe a collection of diseases characterised by progressive loss of cognitive functions and other abilities with a neurological basis that is typically untreatable and irreversible. People living with dementia typically experience a gradual but insidious decline in a wide range of abilities over a number of years, which may ultimately result in them relying on family or formal caregivers to meet all of their needs. As the illness progresses to the later stages, care is often provided in nursing homes or other institutions. As such, staff members need, as this volume emphasizes, to form relationships with and to get to know people who already have significant communication difficulties by the time they meet. As dementia progresses, conversation becomes increasingly challenging and, towards the later stages, verbal language production may disappear altogether.

People living with dementia may make non-verbal attempts to communicate with caregivers, but these are typically ignored, misinterpreted as 'challenging', or judged incomprehensible. These communicative difficulties are not only misinterpreted as signifying that they have nothing to contribute, but that they have actually lost the desire to participate in the social world. People with dementia have typically been given the opportunity to engage in social interactions when they were being helped to eat or assisted with personal care. A lack of social interaction not only leads people with dementia to withdraw from social life, it also has a negative impact on caregivers who may have a tendency to view verbal language production as an indicator of 'emotional connection', making those without verbal language production appear 'unreachable'. Finding alternative methods of communication in the care environment has the potential to improve not only the quality of life of people with advanced dementia, but also the job satisfaction of care staff. The challenge, therefore, is to provide caregivers

of people living with dementia who can no longer speak, with the means to keep interacting and communicating.

How the Book is Organised

Chapter 1, "Both Sides Now Advanced Dementia from the Inside Out", talks of words that are the 'glue' of human existence. They shape our interactions in the world and connect us to other people. Every day we exchange millions of words through conversations, telephone calls, emails, texts and so on. Indeed, we need only think for a moment how many words we have used on any given day and the different ways in which we have used them.

Chapter 2, "We've only just begun", defines the language of dementia and the impact of dementia on relationships. Kitwood's term 'Malignant social psychology' is discussed and the impact of the treatment of people with dementia is considered. Validation therapy and habilitation therapy are described in the section on improving communication.

The chapters which follow explore how non-verbal strategies achieve mutually meaningful interactions in human interactions. Personhood and inter-subjectivity are considered with reference to individual perspectives. A very clear table shows communication skills in communicators with additional needs: healthy infants, people with severe autism and others with advanced dementia. Chapter 3, "I hear you now Collaborative Communication", discusses different means of communication. Chapter 4, "Let's work together: Learning the language of dementia", discusses the Adaptation Interaction Process of communicating together in five steps is very clearly explained: Getting to know you, Communication environment, Identifying the communicative repertoire. Creating a connection and Building the connection. Chapters 5, 6 and 7 tell the stories of individuals with advanced dementia.

Dementia and the urge to communicate

Words enable us to be connected and this desire to be connected is universal. As the book documents, in 2015 there were over seven billion mobile telephone subscriptions across the world - as many as there were people on the planet in 2015. With these multiple channels of communication at our fingertips it is possible to be in touch with other people on a continuous basis. Not only is this big business, as it were, it is fundamental to human existence because humans are social beings, living in social groups and spending our lives interacting and communicating with other people.

The authors explain, that early in their research, they established that the urge to communicate is retained even if words are not. This is indicated in multiple ways through non-verbal means which include sounds, movements, eye gaze and other responses to people in the environment. What is required, as the book emphasizes, is for potential communication partners to recognise and respond to these communication bids from people with dementia who can no longer use words and who find themselves in a different position. It is difficult to see how they can act on their environment to diminish humiliation, not just because they do not have words, but because of the other changes they have probably experienced, such as inability to walk or get out of bed. As such, they rely on other people to enable them to act in the world and to reduce the occurrence of situations where they may experience humiliation. Even though people may no longer be able to use words this does not, as the authors emphasize, mean the end of communication.

In vivid illustration, the authors discuss the care of an Australian woman living with dementia since 2008 and who posted the following blog in 2013:

“Talking eventually becomes an embarrassment or humiliation for a person with dementia. The difficulty with being embarrassed about talking is it tends to isolate [people with dementia] even more. Maybe this is why people with dementia start to give up communicating. Perhaps it is not only the difficulty we have with things like word finding, but also the humiliation of having to listen to ourselves stumble and jumble with our words? Is it simply easier to say nothing than to humiliate ourselves? Humiliation is a powerful social influence and Kate’s words sum up very well the experiences of many people with dementia. They seek to avoid feeling humiliated and so reduce communication and situations when they could interact with others. Arguably this is a normal human response as we generally seek to avoid feeling humiliated”.

Communication is a two-way thing

On reflection, it appears obvious that communication is a two-way thing. We do not communicate alone and, in our communications with other people, be it face to face or remotely, we interact with other people. This activity reminds us of the importance of other people in

communication in that when we encounter someone who has a communication difficulty it is up to us to adjust and modify our behaviour to communicative success. ‘Conversational repair’ as the volume explains, refers to the actions of parties in a conversation to resolve misunderstandings or mis-hearings that occur: the process of conversational repair is ‘collaborative, generally formulaic, and includes problematic utterance(s), the signal of a problem, and the repair of the problem’. People with advanced dementia can repair conversational misunderstandings, but over time the percentage of conversation that necessitates repair increases, placing greater demands on their conversation partner. As conversational repair is collaborative, the role of the partner is crucial. In a study by Orange and associates, conversation partners were family members who had long knowledge and experience of conversations with the individuals with dementia and arguably more vested interest in keeping them going.

Staff in care settings must get to know people with impaired communication and provide opportunities for meaningful social interaction and participation, on this the authors are emphatic. In a study of conversations in care homes, Baker and co-workers identified three types of conversations. The first type was defined by staff initiating topics and doing most of the talking. In the second type of conversation, the amount of conversation was more even and people with dementia initiated some topics. In the third conversation type, people with dementia spoke the most with staff supporting them. Analysis of the different conversation types identified helpful strategies that staff used to keep their partners with dementia engaged, such as repeating back what they said. The authors also highlighted staff behaviours that were unhelpful, such as not fully paying attention and not giving enough time to their partner to speak.

Uncovering and maximising the communication skills that people with dementia retain is crucial for improving their lives. Predictably, this becomes, as the book describes, more difficult to accomplish as communication changes and people lose the ability to use words. The ‘person-centred approach’ described in the volume provides a framework for identifying retained communication skills and an exploration of how these can be maximised to support meaningful interactions between people with dementia and caregivers. The focus here is on identifying and meeting the needs of the person and aims to enhance wellbeing by improving relationships and communication between people with dementia, their families and professional caregivers. ‘Person-centeredness’, then, is achieved when people interacting with the individual focus more on them as a fellow human being than on the illness.

What is Adaptive Interaction?

The authors of the volume talk much about Adaptive Interaction, which is a means of communicating without words. It has been developed to address the communication gap when people with dementia can no

longer use words. Adaptive Interaction grew out of a similar technique termed Intensive Interaction, an established approach well known in the fields of intellectual disability and autism spectrum disorders. Intensive Interaction is an approach that was developed initially to promote communication with people with severe and profound learning disabilities, being based on the fundamentals of communication that typically accompany language acquisition in early life, including, for example, eye gaze, emotional expression and movements. The focus of Intensive Interaction is on learning the communicative repertoire of an individual who is non-verbal, predominantly through observation and imitation. These behaviours, as the authors describe, are thought to represent 'self-talk' on the part of individuals with severe and profound learning disabilities that become the basis of an interaction when mirrored by a communication partner. The caregiver might, for example, copy a sound or action made by the non-verbal person, such as tapping the table. Attending to the other person's behaviour in this manner and responding contingently, the caregiver is able to expand the interaction and to support her partner to take a more active role in communication. By responding in ways that are familiar and meaningful to the person with severe communication difficulties, that is, initially imitating and then developing them into a shared 'language', it is possible, the volume asserts, to build and sustain close relationships without verbal language production. Furthermore, interactions are developed on a day-to-day basis as interaction partners become increasingly attuned to each other and develop their shared language.

Many years ago professionals were fortunate to receive training in the importance of 'learning the language of the individual' from Phoebe Caldwell. The authors relate how Phoebe came to stay with them and enabled them practise the basics of the technique and this experience profoundly influenced their thinking and their approach to using non-verbal communication with people with dementia who can no longer use words. The term 'language' might seem odd when thinking in terms of communicating without words, yet language is more than simply words. As the authors remind us, we come into the world equipped to connect with other human beings. Indeed, babies are born with a set of behaviours, the so-called 'fundamentals of communication' which are designed to trigger a response from parents and caregivers and while initially, this is to ensure survival of the infant, it is also the basis for the development of speech.

To learn the language of a person with dementia who cannot use words, the book focuses on the fundamentals of communication. The study of eye gaze, facial expressions, sounds and movements are all of vital importance here. From this it is possible, as the authors explain, to develop a profile of each person's communication repertoire. Some individuals' repertoires are dominated sounds and others by gaze and yet others by very subtle movements. Everyone, as the authors emphasize, has their own individual repertoire and that it is possible to identify it and use this 'language' to make connections with individuals with dementia who can no longer use words. In so doing,

people with advanced dementia are maintained in the social world. Having learnt their language, it is possible to look for communicative behaviours to focus on and to re-establish a connection. It is also possible to try initiating connections using elements of patients' own repertoires, such as sounds or movements, but it is important that the individual is always allowed to lead. The authors' experience has taught them to be open minded about each interaction and to adapt to each person and each encounter. Through this approach Adaptive Interaction was born.

Clinical case examples

The authors usefully provide some clinical case examples. Chrissie is 78 years old and has been resident in (the fictional) Roseford Care Home for three years. She worked in a mill for most of her working life, enjoying the company of the many friends she had made there. Chrissie, a very outgoing and funny woman, had a 'wicked' sense of humour and would often play practical jokes on colleagues and family members. She loved to sing and would take every chance she could to get a sing-song going at parties at get togethers. Her friends described Chrissie as the life and soul of the party. She and her husband Phil had four children, being happily married for 43 years until Phil died suddenly of a massive stroke. It was only when Phil died that Chrissie's family discovered precisely how much he had been doing for Chrissie 'behind the scenes'. Although it had been previously noticed that Chrissie was having some memory problems, the family had put this down to her 'getting older'. After Phil died, Chrissie was quickly diagnosed with dementia after going outside in her nightdress early in the morning, being found, outside the university building where her daughter Jean worked, at 6 a.m. The police were called and Chrissie became a resident at Roseford Care Home soon after.

Eleanore is 66 years old and has been living in Roseford Care Home for seven years, having been diagnosed with a type of early onset dementia when she was 55 years old. Eleanor has one daughter, Angie, to whom she is very close. She is also married to Mike, a very supportive husband who is devoted to her and to her wellbeing. He describes himself as her husband, not her 'carer' and reacts quickly to anyone who fails to make this distinction. Eleanor's early dementia became apparent when she started to make mistakes at work and the usually self-confident nurse became more and more withdrawn and unsure. She would typically attempt to cover up her mistakes with a joke and a laugh - never for a minute acknowledging that anything was wrong.

Rather than describe here what techniques were employed in communicating with Chrissie and Eleanor, and their effects, I will keep the reader in suspense and refer the reader to the text of the volume at this juncture instead.

Conclusion

This excellent adaptive interaction approach to communicating with people with advanced dementia is essential information for families and professional caregivers, providing a 'language' for communicating with individuals with advanced dementia. People with advanced dementia can then be encouraged to communicate in a way that is both comfortable and meaningful for them.

Effective communication with people with dementia is imperative to good relationships with professional caregivers and family members. This book offers a person-centered approach to assessing the communication skills of people with dementia who are unable to speak and presents evidence-based methods for effective non-verbal communication.

The book is written in a clear and friendly style, avoiding the use of scientific language and providing excellent descriptions of the effect of advanced dementia on communication. There are also sensitively written stories of people with advanced dementia living in a care home. The communicative difficulties experienced by people with dementia may be misinterpreted, as the volume emphasizes, as signifying they have nothing to contribute; in fact, they have actually lost the desire to participate in the social world. As a consequence, individuals with advanced dementia often find themselves excluded from the social world because of appearing 'unreachable.'

The appendix to the volume provides Adaptive Interaction Process Charts which readers could photocopy to record the outcomes they have had with individuals with advanced dementia. The most significant feature of this book are the very powerful stories of people living with advanced dementia which is an excellent way to learn about how lives can be dramatically affected by this illness. This book is highly recommended reading for all those professionals and family carers who care for persons with advanced dementia.

Conflicts of Interest

The author declares no conflict of interest.