

# SCIE RESEARCH BRIEFING

## AIDING COMMUNICATION WITH PEOPLE WITH DEMENTIA

**Definition of a briefing:** A SCIE research briefing is a summary of information on a particular topic to update practice at the health and social care interface. It is a concise document summarising the knowledge base in a particular area to act as a ‘launch pad’ or signpost to more in-depth material. It is produced through a clear methodology involving identification of a focused question, comprehensive searching of multiple sources and filtering of materials for quality.

<b>What is the issue?</b>	Communication is a two-way process and can be defined as, “ <i>person-to-person transmission of ideas through ... language or ... non-verbal media</i> ” (1). Communication “ <i>is a fundamental aspect of all human relationships</i> ” (2) and is an essential element of good care (3). Effective communication can improve the quality of life for a person with dementia. However, experts highlight that people with dementia lack the opportunity to talk and express their feelings about the quality of their own life (4) and services they receive (5). It is vital that people with dementia are consulted on both issues: this can be achieved, given time (5, 6, 7). A number of interventions have been developed to work directly with people with dementia on an individual or group basis and also indirectly with family and professional carers and health/social care professionals (8) to improve communication and quality of life for the individual with dementia and their carers. However, many health and social care professionals have no specific training in dementia care. Factors in communication include the type of dementia a person has, the effects of previous life history and personality, and the current caring environment. On a day-to-day basis, it is vital to enhance communication at all times, take the time to listen and understand, continue in efforts to communicate.
<b>Why is it important?</b>	The onset of dementia can create communication barriers within the person with dementia, such as word-finding problems (9), memory problems (10, 11), using the same words repeatedly, not appearing to understand what it said, saying very little, the use of empty phrases, a lessening ability to be coherent (2) and maintain a conversational topic (12) in which the decline in ability to communicate is progressive (13, 14, 15, 16, 17). Approximately 600,000 people in the UK have dementia: it is estimated that by 2026, there will be 840,000, rising to 1.2 million in 2050 (18). Projections made by the Alzheimer Society are slightly higher (19). Although the numbers involved are substantial, each individual with dementia is different with different communication needs, including people who may have

	<p>additional hearing and visual problems or from minority ethnic communities with English as a second language. Communication difficulties are distressing (11, <a href="#">20</a>) and frustrating (16) for the person with dementia themselves and represents one of the major problems for family carers (<a href="#">21</a>) and care home staff (<a href="#">22</a>, 23). It is vital that communication continues (24), both verbal and non-verbal, despite progression of the condition (2). As far as possible, communication strategies need to be individualised (2, <a href="#">25</a>) to take into account differences between individuals and different degrees of cognitive ability. In the same way, allowance must be made for individual responses to attempts to improve communication (26).</p>
<p><b>What does the research show?</b></p>	<p>Much research has been done in this area of practice. Current research themes include: involving people with dementia and their families in discussions about service quality (27), identifying communication barriers and how to overcome them (28) and developing therapeutic ways for people with dementia to express themselves and communicate: examples are the use of memory aids (23), group meals (<a href="#">22</a>, 29), the mirror as a therapeutic tool (30), music therapy (17), singing by carers (<a href="#">31</a>), dance and movement (<a href="#">32</a>). Other studies have assessed the effectiveness of interventions such as communication training for family carers (33, <a href="#">34</a>) and care home staff (<a href="#">12</a>, <a href="#">35</a>, <a href="#">36</a>), a planned walking/talking programme (16, <a href="#">37</a>), and communication techniques for later-stage dementia (38). Systematic reviews have also been produced for validation therapy (<a href="#">39</a>), reminiscence therapy (40) and Snoezelen (<a href="#">41</a>) and have stated that a drawback to much of the research in this area is that it is small-scale, has limited application to a wider population, uncoordinated and frequently has researcher-identified methodological weaknesses. More systematic research is needed in this area (<a href="#">40</a>) together with more consistency in research (<a href="#">41</a>, 42) and investigation into the effectiveness of combined interventions (<a href="#">1</a>). High-quality qualitative research is also needed to explore the wide variety of approaches that can be used to enable communication.</p>
<p><b>What are the ethical considerations?</b></p>	<p>It is essential to remember that it is a human right and a basic need to communicate with others. People who help and support a person with dementia should also be aware that behaviour is communication and try to develop skills in interpreting behaviour. Care should be taken not to provide too much or inadequate stimulation as this can cause emotions such as fear and anxiety (<a href="#">1</a>) or confusion (11). Advocacy services are useful for people with dementia and can be a means of safeguarding their rights and that their voices are expressed.</p>
<p><b>What do I need to do?</b></p>	<p>Be aware of your own interactions with people who have dementia and be positive and flexible in your approach. Take time to discover the meaning of what is being said. Realise that it is possible to communicate with people at all stages of dementia and develop skills and techniques to do this, including communication skills training and development. Apply the ABC of communication (<a href="#">1</a>): <b>a</b>void confrontation, <b>b</b>e practical, clarify the person’s feelings and offer comfort.</p> <p>Read:</p> <ul style="list-style-type: none"> <li>• The eLSC/SCIE Practice Guide: <i>Assessing the Mental Health Needs of Older People</i> (section 6. Assessing Need: b) Communication) at <a href="http://www.elsc.org.uk/knowledge_floor/bpg2/older.htm">http://www.elsc.org.uk/knowledge_floor/bpg2/older.htm</a></li> <li>• “Aging, Health and Society: News and Views” (Fall 2003) Theme: Strategies for Communication in Dementia at: <a href="http://www.socsci.mcmaster.ca/gerontology/emplibary/newsletter_fall2003_vo19_num1.pdf">http://www.socsci.mcmaster.ca/gerontology/emplibary/newsletter_fall2003_vo19_num1.pdf</a></li> </ul>

	<ul style="list-style-type: none"> <li>• The related SCARE briefing “<i>The Use of Assistive Technology for People with Dementia Living in the Community</i>”.</li> </ul>
<p><b>What are the implications?</b></p>	<p>The starting point for improving communication must be that it is centred on the person with dementia (11) in his/her uniqueness. The barriers to communication, such as physical disability, the effects of medication (8) and the environment, such as noise (11) and lack of staff time (43) need to be tackled in addition to other strategies. The two types of method used to improve communication – practical day-to-day practices (11, <a href="#">15</a>, 43) and more formal projects (<a href="#">12</a>, 16) must include a desire on the part of professionals (and carers) to listen more (23, 43) and talk less (23). A number of strategies are both simple and cost-effective such as planned walking (16), the use of a mirror (30) and toy stimulation (<a href="#">44</a>). Training for carers is an accepted part of care (14) and this must also include informal carers (<a href="#">15</a>, 45). A team approach can be used to develop and implement communication strategies: multi-disciplinary teams (2), including speech-language therapists (8, 14) and dental staff (46) where appropriate. Those assessing and providing personal care to people with dementia need to recognise that, with time and care, individuals can be helped to express themselves more clearly and also contribute to discussions about service evaluation and development.</p>
<p><b>Who can I contact?</b></p>	<ul style="list-style-type: none"> <li>• Alzheimer’s Society at <a href="http://www.alzheimers.org.uk/">http://www.alzheimers.org.uk/</a></li> <li>• Dementia Voice: the dementia services development centre for the South West at <a href="http://www.dementia-voice.org.uk/">http://www.dementia-voice.org.uk/</a></li> <li>• The Dementia Services Development Centres Network at <a href="http://www.dementia.stir.ac.uk/network/network.htm">http://www.dementia.stir.ac.uk/network/network.htm</a></li> <li>• Kingshill Research at <a href="http://www.kingshill-research.org/">http://www.kingshill-research.org/</a></li> <li>• Dementia Advocacy and Support Network (DASN) at <a href="http://www.dasninternational.org/">http://www.dasninternational.org/</a></li> </ul>
<p><b>Where can I find examples of innovative practice?</b></p>	<ul style="list-style-type: none"> <li>• Alzheimer’s Society has produced “<i>The Alzheimer’s Society book of activities</i>” to improve the quality of people’s lives. See: <a href="http://www.alzheimers.org.uk/working_with_people_with_dementia/publications/activities.htm">http://www.alzheimers.org.uk/working_with_people_with_dementia/publications/activities.htm</a></li> <li>• South of Tyne and Wearside Mental Health NHS Trust has developed a Dementia Services Collaborative in the Sunderland and South Tyneside localities. See: <a href="http://www.sunderland.nhs.uk/dsc/default.htm">http://www.sunderland.nhs.uk/dsc/default.htm</a></li> <li>• Stockport Dementia Care Training Project involved development of an education and training package (including communication) for carers. See: <a href="http://www.gmconfed.org.uk/downloads/2003/smallprojects/report2.99.31.pdf">http://www.gmconfed.org.uk/downloads/2003/smallprojects/report2.99.31.pdf</a></li> <li>• Dementia Advice and Support Services (part of the Mental Health Foundation) runs a number of pilot schemes to improve services for people with dementia and their carers. See: <a href="http://www.mhilli.org/dass/dassproject.htm">http://www.mhilli.org/dass/dassproject.htm</a></li> <li>• Storyboard project. Contact: <a href="mailto:liz.wainwright@bradford.gov.uk">liz.wainwright@bradford.gov.uk</a></li> <li>• The Dementia Advocacy and Support Network (DASN) is promoting the involvement of people with dementia in service development. See <a href="http://www.dasninternational.org">http://www.dasninternational.org</a></li> <li>• Alzheimer’s Society has developed strategies to assist people with dementia in participating politically, including having them on their board of trustees. See <a href="http://www.alzheimers.org.uk/News_and_Campaigns/Policy_Watch/involving.htm">http://www.alzheimers.org.uk/News_and_Campaigns/Policy_Watch/involving.htm</a></li> </ul>

<b>What are the views of people who use services?</b>	Research suggests that a high proportion of people with dementia both want and are able to give their opinions on the services received (3). When a number of people with early-stage dementia were asked for their opinions on services received, it was evident that they “... <i>do not have a uniformity of experience – a voice – but instead have individual, articulate voices that speak of unique life experiences.</i> ” (47)
<b>Resource sites</b>	<ul style="list-style-type: none"> <li>• Search <a href="#">CareData</a> freely available via the <a href="#">Electronic Library for Social Care</a></li> <li>• The <a href="#">Journal of Dementia Care</a></li> </ul>
<b>Comments</b>	Please address all comments, suggestions or ideas for improvement to the ScHARR Library at <a href="mailto:scharlib@shef.ac.uk">scharlib@shef.ac.uk</a>
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