

# Dementia Gateway: Communicating well

---

## Key messages

- Good communication is a fundamental aspect of support for people with dementia.<sup>1</sup> But care staff see communication problems as one of the greatest challenges in delivering good dementia care.<sup>3</sup>
- Quality of life is an important concept and ‘the ability to communicate’ is one of 10 key indicators of quality of life valued by people with dementia.<sup>4</sup>
- In care home settings, many people with dementia communicate through what may be seen as challenging behaviour,<sup>3,11</sup> especially if staff do not communicate well.
- For people with more advanced dementia, non-verbal communication may be the main way for them to express their preferences<sup>5</sup> and it is important that staff recognise this.
- Staff need to recognise that a person’s mood, level of concentration and motivation to get involved in conversation may be different in different settings, but also at different times of the day and in response to other circumstances.<sup>5</sup>
- Life story work is one way for care home staff to communicate and develop relationships with residents based on their unique life experiences.<sup>18,20</sup>
- Staff and family members should be aware that making changes to the environment can help people with dementia to communicate better.<sup>21</sup>
- There is not much research on communication with people with dementia in community settings, such as in people’s own homes or in day care settings, and little in the way of the involvement of older people with dementia.

## Introduction

This summary highlights key messages from the research on communicating well with people with dementia. It is not intended to be a comprehensive review of the literature on this topic. The material on which this summary is based was identified through focused searching of the literature published from 2008 to 2012. Some material pre-dating 2008 is also referred to in order to illustrate a point that was not covered in the identified literature.

## What is the issue?

Communication is a fundamental aspect of all human relationships.<sup>2</sup> However, care staff see communication problems as one of the greatest challenges in delivering good dementia care.<sup>3</sup> When people with dementia are enabled to communicate, they have important things to say about how dementia affects them, and about what they think is important about their lives now and in the future, including how services should see that their health and social care needs are met.<sup>5</sup> But helping people with dementia to express their views can be difficult because of cognitive (thinking, reasoning and remembering) decline and communication problems that are related to the condition.<sup>7</sup>

Good communication is a two-way process and a crucial element in providing person-centred care to someone with dementia<sup>25</sup> (that is, care that is tailored around an individual's needs and preferences, values and beliefs, life history and other things that are important to a person<sup>10</sup>). It is about care staff, family and others communicating in a sensitive way

and helping the person with dementia to communicate. But many social care and health staff find it difficult to communicate with people with dementia.<sup>10,11</sup> With advanced dementia, the challenge is significant as verbal and cognitive (thinking, reasoning and remembering) skills get affected, which means that staff, carers and people with dementia must be aware that abilities will change over time,<sup>11</sup> and this can be frustrating for everyone concerned.<sup>5</sup>

## The status of research

One weakness of much of the research in this area is that it is small-scale, in general the results of studies may not apply to people who didn't take part in the studies and often there are problems with how the studies are designed and the methods that are used.

Also, there is not much research set in the community, such as in people's own homes and in day care settings, and little in the way of the involvement of older people with dementia.

More research is needed to address these gaps as well as investigating the wide variety of ways in which people can be helped to communicate better. Certain communication tools such as Talking Mats® have proved effective (for more information on these, see the section 'Effective communication tools and strategies' later in this overview) but there should be more research with people at different stages of dementia.<sup>15</sup>

It is important that people with dementia are included in research because they are able to communicate<sup>25</sup>

and what they say will make a valuable contribution to what we know about dementia.<sup>5,6</sup>

## The importance of communication

The effect of dementia on the person is profound and problems usually include loss of memory, loss of language, mood changes, declining ability to reason and understand, loss of communication and problems managing everyday tasks.<sup>3,15,17,19</sup>

Communication problems include a 'decline in the ability to talk, read and write'.<sup>17</sup> A person with dementia may also get more confused and find it hard to keep hold of a sense of who they are, making their need for communication with others even more important.<sup>10</sup>

As dementia progresses, people find it more and more difficult to express themselves and be involved in planning and care decisions that affect them<sup>15</sup> and care staff can struggle to identify and manage the cause of disturbed behaviour.<sup>22</sup> The rate of decline in dementia is a unique experience for each person and is affected by many things, including the type of dementia the person has, their physical make-up, how emotionally strong they are and the support that is available.<sup>17</sup> Communication is a fundamental part of that support – it is central to providing good dementia care<sup>1</sup> or as one study suggests: 'communication is caring'.<sup>10</sup>

## Communication and person-centred care

Most research about communication and dementia recognises the importance of person-centred care.<sup>10</sup>

This approach is about moving away from a 'medical model' – which focuses on the disease – to one that centres on the person using services and is delivered in a way that encourages independence, autonomy (the freedom to act, behave and so on in the way the person wants) and choice.<sup>23</sup> This includes being aware of and appreciating a person's needs and preferences as well as their life history, attitudes, beliefs, values, culture, religion and other attributes that are part of their make-up.<sup>10</sup>

## Communication from the perspective of the person with dementia

### Quality of life

People communicate their needs, wishes and feelings as a way of maintaining quality of life and protecting a sense of identity.<sup>1</sup> Quality of life is an important concept and research by the Alzheimer's Society, drawing on the views and experiences of people with dementia, identified the 'the ability to communicate' as one of 10 key indicators of quality of life that were valued by people with dementia.<sup>4</sup> Where communication is compromised, this can affect quality of life.<sup>2</sup> This was highlighted in a study of care homes where there was clear evidence that poor staff communication with people with dementia had a significant negative effect on the quality of life of residents with dementia.<sup>23</sup>

### Examples of communication problems

Communication problems are related to the type and cause of dementia and can include: having a reduced vocabulary; having problems with reasoning; repeating previously used words, phrases and

behaviour; being incoherent; not being able to follow a topic; having problems in finding words; and having a tendency to be distracted.<sup>15</sup> But despite these restrictions, people with dementia are capable of conveying their feelings and concerns clearly,<sup>6</sup> and they can also do so to some extent in the later stages of dementia.<sup>4,8,9</sup>

### **Non-verbal communication**

People with more advanced dementia may be able to express their preferences best by non-verbal communication<sup>5,10</sup> (for example, facial expression, gestures, body posture and eye contact) and it is important that staff recognise this. Simply because verbal communication is non-existent does not mean that it is impossible to engage with people who are not able to communicate verbally. For all of us, over 80 per cent of communication is non-verbal and so we do have other ways of connecting with people to draw on.<sup>24</sup>

## **Communication from the perspective of staff**

### **Knowledge and skills**

In a large study of care homes by the Alzheimer's Society, care home staff said that communication problems were one of the main challenges as far as providing good dementia care was concerned.<sup>3</sup> But the quality of staff communication can be compromised by various issues. Not having the right knowledge and skills is one key issue.<sup>3,23</sup>

Communication is also hampered by poor staff attitudes and reliance on stereotypes about people

with dementia, and a lack of awareness of the distinct problems that people with dementia face.

### **External factors**

Communication problems can also be a result of things associated with the work environment, such as access to training, a focus on getting tasks done and not enough resources<sup>25</sup>. For instance, in one study of care homes, residents wanted opportunities for social interaction with staff, but managers put an emphasis on completing a daily sequence of care tasks efficiently, which prevented this from happening.<sup>25</sup> Some or all of the sequence of care tasks were carried out non-verbally using gestures, guiding residents with touch and physical handling. Carers' speech was related to the level a resident complied with a care task so that if a resident didn't comply, there was more carer speech, which the authors described as 'care-speak'.<sup>25</sup> In these situations, verbal responses or reactions from residents were not sought and rarely needed.

## **When communication is not person-centred**

### **Losing out on communication**

Where staff or carers do not communicate properly, the person with dementia may, over time, be gradually deprived of the power to make their own choices, their rights become worn away and other people make choices for them.<sup>12,13,14</sup> An example would be where a person with advanced dementia does not have a say about what they eat at mealtimes because care home staff have imposed

their own choice based on their assumptions about what the resident would enjoy.<sup>23</sup>

### **Impact on mood**

The quality of communication has a big impact on how people with dementia feel: there is a strong link between positive, friendly communication and improved mood in people with dementia; and between negative communication and a decreased feeling of wellbeing.<sup>23</sup> It seems that 'neutral' styles of communication, which are characteristic of a focus on tasks rather than the person, are also linked with residents appearing to be withdrawn or depressed because staff do not show empathy and warmth.<sup>23</sup>

### **The effect of negative stereotypes**

If workers ignore people with dementia or communicate with them on the basis of stereotypes about people who have problems with thinking, knowing and remembering (people who are cognitively impaired), this can have a negative effect on communication over time.<sup>10,16</sup> If staff do not communicate then the needs, abilities and potential of people with dementia are ignored, and this increases their feelings of helplessness and worthlessness.<sup>10</sup> This then curbs the desire of people with dementia to engage and reduces their ability to do so effectively, which in turn reinforces stereotypical judgements and increases staff apathy.<sup>10,25</sup> This illustrates how the capacity of the person with dementia to communicate their choices, wishes and needs can be worn away.<sup>26</sup>

### **Challenging behaviour**

In care home settings, many people with dementia communicate through what may be seen as challenging behaviour – such as hitting out or being aggressive, which may be managed with a sedative drug.<sup>3,11</sup> Dementia specialists believe that challenging behaviour is a response to frustration at not being able to communicate.<sup>27</sup> This behaviour may be seen in situations where residents are not listened to and their needs are ignored,<sup>22,28</sup> or where they have language disorders or suffer pain or discomfort.<sup>22,29</sup>

### **Increased isolation and exclusion**

Problems with communication can lead to greater isolation and exclusion for people with dementia and difficulty in bonding with others, as well as to an increase in the risk of being neglected and ignored.<sup>3,11</sup> In a study of 12 care homes, there was evidence that staff avoided meaningful communication. Over a six-hour period, it was noticed that, apart from direct care interactions, half the residents spent less than two minutes in communication or conversation with staff or other residents.<sup>3,11</sup> When communication does happen this can sometimes be patronising and compared with that of speaking with young children, often labelled as 'elderspeak'.<sup>10,30,31</sup>

## Encouraging person-centred communication

### Exploring appropriate tools and strategies

Speech, writing, gesture, tone of voice, gaze and posture help engagement and communication.<sup>22</sup> Staff and managers need to identify appropriate tools and strategies like these that they can use when communicating with a person with dementia.

### Sensory loss

When hearing or sight deteriorates, this affects communication,<sup>5</sup> but equipment such as hearing aids or access to a British Sign Language interpreter may help. For those with dual sensory loss (that is, both hearing and sight problems), problems with communicating are escalated even further. People with problems caused by sensory or cognitive (thinking, knowing and remembering) impairment may turn away from those who try to communicate with them.<sup>32</sup> Hearing and sight loss are common disorders in older adults but their effects on communication are not well documented.<sup>33</sup>

### Fluctuating abilities

A person's mood, level of concentration and motivation to get involved in conversation may vary in different settings, but also at different times of the day and in response to other things.<sup>5</sup> Staff need to be sensitive to this and must be conscious that their own mood, stamina, and ability to concentrate will affect the way they communicate with people.<sup>5</sup>

### Culture and language

Language barriers with older members of minority ethnic communities who only have limited use of English, or who have reverted to their native tongue with advancing dementia, may be an issue.<sup>5,34</sup> It is important that care staff are able to understand and respond in people's chosen, or first, language.<sup>23</sup> If not, access to people who can act as interpreters and have matching language skills and cultural understanding is important.<sup>5</sup>

### Working with family members

Family members can have an important role to play in helping with the involvement and communication of a person with dementia.<sup>3</sup> In particular, they can provide useful information that can help staff to understand and communicate more effectively with the person.<sup>3</sup> In some situations, however, relatives can have a negative impact on the involvement of the person – for example, at meetings where they may take control and speak on behalf of the person with dementia.<sup>5</sup>

### Environment

Communication is affected by environmental factors.<sup>21</sup> A person with dementia may find it difficult to concentrate on many things at once and become overwhelmed in noisy or unfamiliar environments and in social situations.<sup>2,19,35</sup> Sounds like the TV, washing machine and vacuum cleaner can be very distracting. The importance of good lighting should also not be ignored.<sup>35,36</sup> Staff and family members should be aware that making changes to the environment can help people with dementia to communicate better.<sup>21</sup>

## Effective communication tools and strategies

There are various communication tools for supporting good communication with people with dementia and, indirectly, with family and professional carers and health/social care professionals. These help to support people in their decision making and provide an opportunity for meaningful activity. Some are outlined below.

### **Life story work and reminiscence therapy**

Life story work can provide an effective way for care home staff to communicate and develop relationships with residents based on their unique life experiences.<sup>18,20</sup> This would be true in other care settings too. The approach helps others to understand the meaning behind what people say; improve understanding of behaviour; and it reinforces individual identity through interaction and relationships.<sup>37</sup> Life story tools and techniques include journals, story boards and memory boxes.

Reminiscence therapy is one of the most popular interventions in dementia care that have a focus on the psychological and social needs of the person.<sup>38</sup> Reminiscence can be supported through resources such as pictures, memory books and personal objects<sup>15</sup> and can be a sensible and simple approach for improving communication with people with dementia and care staff.<sup>22</sup>

### **Talking Mats®**

This low-tech communication framework uses a textured mat and visual symbols to help people

express their views on various topics and helps with communication at all stages of dementia.<sup>15</sup> Talking Mats are an effective way of helping people at all stages of dementia to communicate.<sup>15,42</sup> The benefits are seen in the involvement of the person with dementia, their understanding and their ability to follow discussions and make their personal views understood.<sup>15</sup> People with dementia say that Talking Mats help them to clarify their thoughts and make their views heard.<sup>7</sup> Because of its use of picture symbols, Talking Mats may be useful for people whose first language is not English or who revert to their native tongue as their dementia advances.<sup>15</sup>

### **Building communication strategies into care tasks**

Care home staff can communicate better with residents who have dementia by building communication strategies into everyday care tasks.<sup>22</sup>

### **Single-task activities**

Single-task activities, such as life story work or a one-to-one conversation, carried out at fixed times help to improve communication.<sup>22</sup> Single - as opposed to multi-task activities are probably more effective because people with dementia cannot manage several tasks at the same time.<sup>39</sup>

### **Toolkits**

The Dementia Toolkit for Effective Communication (DEMTEC) is suitable for a wide range of people working in health and social care.<sup>10</sup> It was developed after consulting with people with dementia, their families and health and social care professionals. It

uses simple, accessible strategies with which to improve communication.

### **Other methods**

Other methods such as art therapy, music therapy and drama therapy may have a useful role in providing opportunities for communication and self-expression.<sup>18</sup>

### **Implications from the research**

Good communication benefits the person living with dementia, staff and others.<sup>10</sup> The quality of staff communication with people with dementia has a huge impact on their quality of life.<sup>23</sup> Ways of communicating need to be person-centred, taking account of the different backgrounds, life histories, needs and values of people with dementia and their different levels of cognitive (thinking, knowing and remembering) ability.

The work environment (such as a care home) needs to be conducive to good communication. It needs to be alert to 'getting the task done' attitudes and circumstances where staff actively avoid communication with residents. Care home policies and standards should include good communication expectations.

Focused training programmes for care staff for use in daily care situations can improve skills in verbal and non-verbal communication among care staff and have positive outcomes for people with dementia.<sup>3,11</sup> And training gets the best results when it is part of a broader commitment to the improvement of quality in the care home.<sup>40</sup> Training and quality improvement must be tailored to care staff, some of whom may not have English as a first language.<sup>11</sup> A National Audit Office report found that in care homes there is no obligation for staff to be trained in communication with residents<sup>41</sup> and this is where policy needs to be changed to address these gaps.



## References

1. Jootun, D. and McGhee, G. (2011) 'Effective communication with people who have dementia', *Nursing Standard*, vol 25, no 25, pp 40–46.
2. Richter J.M., Roberto K.A. and Bottenburg, D.J. (1995) 'Communicating with persons with Alzheimer's disease: experiences of family and formal caregivers', *Archives of Psychiatric Nursing*, vol 9, no 5, pp 279–285.
3. Alzheimer's Society (2007) *Home from home: A report highlighting opportunities for improving standards of dementia care in care homes*, London: Alzheimer's Society.
4. Alzheimer's Society (2010) *My name is not dementia: People with dementia discuss quality of life indicators*, London: Alzheimer's Society.
5. Cantley, C., Woodhouse, J. and Smith, M. (2005) *Listen to us: Involving people with dementia in planning and developing services*, Newcastle: Dementia North, Northumbria University.
6. Von Kutzleben, M., Schmid, W., Halek, M., Holle, B. and Bartholomeyczik, S. (2012) 'Community-dwelling persons with dementia: what do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia', *Aging and Mental Health*, vol 16, no 3, pp 378–390.
7. Oliver, T.M., Murphy, J. and Cox, S. (2010) "She can see how much I actually do!" Talking Mats®: helping people with dementia and family carers to discuss managing daily living', *Housing, Care and Support*, vol 13, no 3, pp 27–35.
8. Claire, L., Rowlands, J., Bruce, E., Surr, C. and Downs, M. (2008) 'The experience of living with dementia in residential care: an interpretative phenomenological analysis', *The Gerontologist*, vol 48, no 6, pp 711–720.
9. Lawrence, V., Samsi, K., Banerjee, S., Morgan, C. and Murray, J. (2011) 'Threat to valued elements of life: the experience of dementia across three ethnic groups', *The Gerontologist*, vol 51, no 1, pp 39–50.
10. Young, T. (2012) 'Devising a dementia toolkit for effective communication', *Nursing and Residential Care*, vol 14, no 3, pp 149–151.
11. Alzheimer's Society (2007) *Submission to the All Party Parliamentary Group Dementia Workforce Inquiry* ([www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=543](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=543)), accessed 14 February 2013).
12. Cheston, R., Bender, M. and Byatt, S. (2000) 'Involving people who have dementia in the evaluation of services: a review', *Journal of Mental Health*, vol 9, no 5, pp 471–479.
13. Kitwood, T. (1997) *Dementia reconsidered: The person comes first*, Buckingham: Open University Press.

14. Tyrell, J., Genin, N. and Myslinski, N. (2006) 'Freedom of choice and decision making in health and social care: views of older patients with early-stage dementia and their carers', *Dementia: The International Journal of Social Research*, vol 5, pp 479–502.
15. Murphy, J., Gray, C.M., van Achterberg, T., Wyke, S. and Cox, S. (2010) 'The effectiveness of the Talking Mats framework in helping people with dementia to express their views on well-being', *Dementia*, vol 9, no 4, pp 454–472.
16. Savundranayagam, M., Ryan E. and Hummert, M. (2007) 'Communication, health and ageing: promoting empowerment', in A. Wetherall, B. Watson and C. Gallois (eds) *Language, discourse and social psychology*, Basingstoke: Palgrave Macmillan: Basingstoke, pp 81–107.
17. Knapp, M., Albanese, E., Banerjee, S., Dahnasiri, S., Fernandez, J.-L., Ferri, C., McCrone, P., Prince, M., Snell, T. and Stewart, R. (2007) *Dementia UK: A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London and the London School of Economics*, London: Alzheimer's Society.
18. Department of Health (2009) *Living well with dementia: A national dementia strategy*, London: Department of Health.
19. Ryan, E., Bannister, K. and Ann, P.A. (2009) 'The dementia narrative: writing to reclaim social identity', *Journal of Aging Studies*, vol 23, no 3, pp 145–157.
20. Institute for Research and Innovation in Social Services (2010) *Supporting those with dementia: Reminiscence therapy and life story work*, Glasgow: Institute for Research and Innovation in Social Services.
21. Brush, J., Sanford, J., Fleder, H., Bruce and Calkins, M. (2011) 'Evaluating and modifying the communication environment for people with dementia', *Perspectives on Gerontology*, vol 16, no 2, pp 32-40.
22. Vasse, E., Vernooij-Dassen, M., Spijker, A., Rikkert, M.O. and Koopmans, R. (2010) 'A systematic review of communication strategies for people with dementia in residential and nursing homes', *International Psychogeriatrics*, vol 22, no 2, pp 189–200.
23. Commission for Social Care Inspection (2008) *See me, not the dementia: Understanding people's experiences of living in a care home*, Newcastle-Upon-Tyne: Commission for Social Care Inspection.
24. Chapman, A. (2009) 'Communication', *Dementia Now*, vol 6, no 4, Stirling: Dementia Services Development Centre.
25. Ward, R., Vass, A.A., Aggarwal, N., Garfield, C. and Cybyk, B. (2008) 'A different story: exploring patterns of communication in residential dementia care', *Ageing and Society*, vol 28, no 5, pp 629–651.

26. Scottish Government (2011) *Promoting excellence: A framework for all health and social services staff working with people with dementia, their families and carers* (www.scotland.gov.uk/Publications/2011/05/31085332/0, accessed 4 July 2013).
27. Branfield, F. and Beresford, P. (2010) *A better life: Alternative approaches: A service user perspective*, York: Joseph Rowntree Foundation.
28. Hancock, G.A., Woods, B., Challis, D. and Orrell, M. (2006) 'The needs of older people in residential care', *International Journal of Geriatric Psychiatry*, vol 21, pp 43–49.
29. Husebo, B.S., Ballard, C. and Aarsland, D. (2011) 'Pain treatment of agitation in patients with dementia: a systematic review', *International Journal of Geriatric Psychiatry*, vol 26, no 10, pp 1012–1018.
30. Williams, K.N. (2006) 'Improving outcomes of nursing home interactions', *Research in Nursing and Health*, vol 29, no 2, pp 121–133.
31. Williams, K., Kemper, S. and Hummert, M.L. (2003) 'Improving nursing home communication: an intervention to reduce elderspeak', *The Gerontologist*, vol 43, no 2, pp 242–247.
32. Fitzgerald, R. and Parkes, C. (1998) 'Blindness and loss of other sensory and cognitive functions', *British Medical Journal*, vol 316, no 7138, pp 1160–1163.
33. Heine, C., Erber, N.P., Osborn, R. and Browning, C.J. (2002) 'Communication perceptions of older adults with sensory loss and their communication partners: implications for intervention', *Disability and Rehabilitation*, vol 24, no 7, pp 356–363.
34. Moriarty, J., Sharif, N. and Robinson, J. (2011) *Black and minority ethnic people with dementia and their access to support and services*, London: Social Care Institute for Excellence.
35. Stirling University (2010) *10 helpful hints for dementia design at home*, Stirling: Stirling University Dementia Services Development Centre.
36. Torrington, J.M. (2007) 'Lighting for people with dementia', *Lighting Research and Technology*, vol 39, no 1, pp 81–97.
37. McKeown, J., Clarke, A., Ingleton, C., Ryan, T. and Repper, J. (2010) 'The use of life story work with people with dementia to enhance person-centred care', *International Journal of Older People Nursing*, vol 5, no 2, pp 148–158.
38. Dodd, K. (2010) 'Psychological and other non-pharmacological interventions in services for people with learning disabilities and dementia', *Advances in Mental Health and Learning Disabilities*, vol 4, no 1, pp 28–36.
39. Petterson, A.F., Olsson, E. and Wahlund, L.O. (2007) 'Effect of divided attention on gait in subjects with and without cognitive

- impairment', *Journal of Geriatric Psychiatry and Neurology*, vol 20, no 1, pp 58–62.
40. Moriarty, J., Kam, M., Coomber, C., Rutter, D. and Turner, M. (2013) *Communication training for care home workers: Outcomes for older people, staff, families and friends*, London: Social Care Institute for Excellence.
  41. National Audit Office (2010) *Progress in improving stroke care*, London: The Stationery Office.
  42. Macer, J. and Murphy, J. (2009) *Training care home staff to use Talking Mats®: with people who have dementia*. York: Joseph Rowntree Foundation.

**[www.scie.org.uk/dementia/living-with-dementia/communication/index.asp](http://www.scie.org.uk/dementia/living-with-dementia/communication/index.asp)**