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## **Optimising communication between medical professionals and people living with dementia**

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**Abstract**

**Background:** A growing body of research evidence indicates that improving communication with people living with dementia (PLWD) has a positive effect on their quality of life. Policy initiatives internationally highlight prevalent poor communication practices in care environments in general and medical contexts in particular as priority areas for improvement. Currently available communication interventions exhibit shortcomings, and their application remains unusual.

**Method:** A spectrum of multidisciplinary professional and lay stakeholders, including PLWD, took part in an iterative consultation process in the United Kingdom. This aimed to develop a communications advice package which would meet their needs, and involved observation of practice in a variety of care contexts and semi-structured focus group and individual interviews.

**Results:** Lay participants reported dissatisfaction with current communicative practices, particularly during contact with medical professionals. Both lay and professional participants reported general dissatisfaction with currently available communication advice. An agreed version of a dementia toolkit for effective communication ('DEMTEC') was produced. This consists of three 'levels'. The foundation Level 1 details beliefs about the psycho-social effects of dementia on communication, as well as empowering approaches to communication involving PLWD. Level 2 consists of practical considerations and advice in 8 key areas. Level 3 uses case studies to show how the principles and advice in preceding levels are applicable to individuals in different care contexts and at different stages of dementia.

**Conclusion:** The project has produced a free-to-users instrument that is empirically supported and adaptable to individual PLWD and to a range of health, care and sociocultural environments.

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**Keywords:** Care, Quality of Life, empowerment, toolkit, training.

**Running title:** Optimising Communication with people with dementia

## **Introduction**

Recent United Kingdom (U.K.) policy initiatives have highlighted quality of life (Department of Health and the Medical Research Council, 2009; Department of Health (DoH), 2009) and communication (Commission for Social Care Inspection (CSCI), 2008) as target areas for improvement in dementia care, with similar initiatives emerging internationally (Alonso *et al.*, 2010; Beer *et al.*, In Press). In both the home environment and in institutional care, communication with PLWD is often less than optimal, with evidence-based carer communication training a rarity (CSCI, 2008). The care provided by medical professionals in hospitals and the community has also come under scrutiny. Within hospitals there is a perception from Consultant Old Age Psychiatrists, that non-specialist staff are poorly informed in their knowledge of dementia and that little progress is being made in co-ordinating generalist dementia training (National Audit Office, 2010a/b). In the community, only 31% of General Practitioners felt that they had sufficient dementia training and 70% felt they had too little time with PLWD (National Audit Office, 2007). In either context, good communication has been highlighted as a key component from the very start of the therapeutic relationship (Pinner and Bouman, 2003). Continuing professional

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education for all groups aiming to improve care for PLWD has been recommended by a number of authorities (DoH, 2009; National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (NICE-SCIE), 2006).

Care for PLWD in general non-dementia specialist hospital environments has been criticised by all stakeholders, and places considerable demands on overstretched staff and accommodation. In the U.K., PLWD over 65 years of age are currently occupying up to a quarter of all National Health Service hospital beds at any one time. Evidence suggests that PLWD spend considerably longer in hospital than is the case for non-dementia patients with similar medical problems. A large majority, 89%, of nursing staff identified working with people with dementia as challenging (Alzheimer's Society, 2009). There is evidence to suggest that poor communication with PLWD may cause significant harm including contributing to loss of cognitive ability as a result of a downward spiral in interpersonal communication where perceived deficits are reinforced and genuine abilities are insufficiently supported. Research suggests that improving communication may have positive effects on PLWD, on informal (usually family member) carers, and on people working in formal care environments (for a systematic review of recent research into communication strategies for people with dementia in residential and nursing homes, see Vasse, *et al*, 2010). A number of studies have demonstrated that communication training for staff in long-term care institutions has direct benefits for residents living with dementia (Savundranayagam *et al.*, 2007a; Savundranayagam, *et al.*, 2007b; Peterson *et al.*, 2002). Reciprocally, effective communication with PLWD may also improve staff morale, increase job satisfaction and reduce staff turnover (Savundranayagam *et al.*, 2007a; Savundranayagam *et al.*, 2007b; Zimmerman *et al.*, 2005).

Internationally, there are numerous examples of published guides to improving communication with PLWD aimed at different user groups such as long-term care assistants, health professionals such as nursing staff, and family members of PLWD (e.g. Alzheimer's Society, 2010a; Dodd *et al.*, 1990; Goldsmith, 1996; Mace and Rabins, 1999; Santo Pietro and Ostuni, 2003; Williams, 2005). Although much of the advice offered is pragmatic and helpful, and often based on personal expertise, communication strategies based on empirical research or any theoretical framework are rare (Young *et al.*, 2011). Moreover, their content rarely if ever incorporates the specific perspective of all stakeholding groups, particularly PLWD whose input has historically been underrepresented in research (Young, Manthorp and Howells, 2010). Take up of the advice, and its application to care has, perhaps as a consequence, been very unusual (Department of Health and the Medical Research Council 2009; CSCI 2008).

The aim of this project was to address the acknowledged need for improved communication with PLWD by developing a new intervention (later named 'DEMTEC') involving a range of stakeholders, including PLWD and their carers which would be grounded in theory and the available empirical evidence, and which was related to the experiences and needs of end-users. A solid theoretical foundation and a high relevance to stakeholders would, it was hoped, increase the relevance of the toolkit and so increase its application. Development of an instrument which was adaptable to the needs of individuals in different care environments, in diverse sociocultural contexts, and over time, was also a primary aim.

## **Methods**

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The following research questions were the focus for this study:

1. How useful and relevant is extant communications advice to its different audiences?
2. How much of it is applied to care?
3. Can advice be indexed in such a way as to be both comprehensive and applicable to the needs of individuals (both PLWD and carers)?

Preliminary work consisted in the first instance of the observation of practice in different care environments in the U.K. (general and dementia-specialist long term care institutions, day-care centres and psycho-geriatric wards). Semi-structured interviews with professionals, including residential home managers, care workers, nurses and physicians were then conducted. The views of PLWD and their informal carers were also sought in this second stage. There were numerous reports from them of poor communication between PLWD and healthcare professionals. Criticism included PLWD being frequently subjected to patronising speech. Both PLWD and their informal carers also frequently expressed beliefs that their concerns had not been listened to, and also noted a lack of real communicative engagement by medical professionals (non-dementia specialists such as general practitioners especially). Important communication episodes, especially the point of diagnosis, were highlighted as being badly handled by practitioners. All professional participants during this preliminary stage reported that they had had no specific training in communicating with PLWD. Both lay and professional participants confirmed that there was a perceived lack of suitable practical guidance and little availability of training on communication with PLWD. Criticisms of existing communication guides from both lay and professional participants are summarised in Table 1, below.

----- *Please insert Table 1 near here* -----

In response to these initial findings, a larger-scale project to capture experience and opinion was devised. Consultation with a range of U.K.-based stakeholders was initiated using the “Code of Practice for Communicating with People Living with Dementing Illnesses” (CoP), a summary of the findings of the preliminary work (Young & Manthorp, 2009). Participating stakeholders were asked to reflect in detail on their own experiences of communication in relation to dementia, and to comment on whether the CoP was representative of good practice. PLWD and family members were interviewed independent of any direct influence by professionals or paid carers in order to try and ensure that this previously underrepresented group could express their views in a “safe” environment.

Data collection was carried out in a variety of environments (chiefly the homes of PLWD, or Alzheimer Society premises) and a total of 79 people contributed to this stage of the process. Of these, 31 were PLWD, 19 were informal carers (usually family members of the PLWD) and 29 were professionals. The professionals consisted of 6 dementia care specialist nurses; 5 health and communications researchers; 4 managers of long-term general and dementia care specialist institutions; 4 senior administrators for long-term care providers (housing associations and local authorities); 4 from the Alzheimer’s Society (care and communications specialists); 2 old age registered general nurses; 2 professional care specialists from non-dementia organisations and 2 speech and language therapists.

The CoP presented pilot data using the “3-level” structure, later adapted for use in DEMTEC. Level 1 was intended as a clear and agreed statement by UK-based stakeholders of their beliefs about dementia, the psycho-social effects of dementia on

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communication, and empowering approaches to communication involving individual PLWD. Level 2 consisted of 10 specific components of good communication practice that were consistent with the philosophy of Level 1. Each component consisted of a ‘what’, a ‘why’ and a series of ‘hows’, i.e. a brief definition, a rationale for including this component in the CoP and a list of implications for, and specific guidance on effective communication practices related to this component. Level 3 of the CoP consisted of practical advice about how the advice in level two could be operationalised and individualised to the needs of specific PLWD.

### **Results**

It was felt by the majority of stakeholders that “Code of Practice” as a title was too prescriptive and potentially off-putting. Participants agreed that a “toolkit” was a more appropriate title, reflecting a guide that was advisory rather than compulsory. The acronym DEMTEC (Dementia Toolkit for Effective Communication) was suggested by a PLWD and was readily adopted. Table 2, below, gives an overview of DEMTEC’s structure and contents, and Table 3 gives an example of a Level 2 component in full. This details the advice given regarding making the care or home environment as conducive as possible to good communication practices.

*----- Please insert Table 2 near here -----*

*----- Please insert Table 3 near here -----*

Participants confirmed their preference for the formulation PLWD (people living with dementia) rather than “people with dementia” or “patients with dementia” which

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was felt to over-emphasize the condition at the expense of individuality. The language of the toolkit was felt to be appropriate for both a lay and a multidisciplinary professional audience, although it was suggested that language could be simplified further for users who may have some difficulties with English, for whatever reason.

The overall “3-level” structure of the toolkit was viewed by both groups as accessible and fit for purpose (Table 2). The majority of participants felt that Level 1 was a necessary foundational statement about the importance of effective communication with PLWD. A number of changes to the “how” advice of Level 2 were agreed, reducing it from 10 components to 8 and simplifying the language used. Level 2 components, a rationale for the inclusion of each one, and the specific advice came from lay and professional participants.

In order to show how Level 3 might serve its function of individualising the principles in Level 1, and the advice in Level 2, participants agreed that case studies of PLWD would effectively illustrate the communication principles laid out by DEMTEC. It was also felt, particularly by the professional participants, that the scenarios should reflect the likely effects of dementia on communication at different stages of the condition. While anxious to dispel ideas that there are ‘typical’ experiences of dementia, professional participants also felt that there were enough communicative common features involved in living with dementia in its broadly early-to-middle and later stages to warrant advice of specific relevance to both groups. In response to these opinions, 5 case studies were produced demonstrating how communication might be made more effective by incorporating advice from DEMTEC. It was suggested by participants that the case studies could also be used as the basis for multidisciplinary professional training.

## **Discussion**

The DEMTEC consultation process highlighted frequent incidents of less than adequate communication between medical professionals and PLWD, reiterating the pressing need to improve medical education about dementia that has recently been raised by a key U.K. policy initiative (DoH, 2009). Although there are some examples of educational interventions to improve communication between medical trainees and PLWD internationally (Robinson *et al.*, 2010; Goldstein *et al.*, 1999), undergraduate teaching time devoted to dementia, at least in the U.K., is variable. Moreover, it is unclear whether qualified physicians go on to receive further training in the postgraduate environment (Tullo *et al.*, 2010). DEMTEC has a potentially valuable role in dementia-specific training for both undergraduate students and non-specialist physicians in the later stages of their training, particularly in the development of appropriate communication skills.

Given the acknowledged need for ongoing training for healthcare professionals working with PLWD, DEMTEC has a number of potential applications as a training tool. The underlying principles of good communication set out by DEMTEC (Table 2) are highly relevant to the clinical environment and staff could be encouraged to think about whether the daily care that they provide to individual patients appears to fit the model, or whether small modifications could be made to improve communication. DEMTEC includes a number of “case studies” – examples of the challenges of providing appropriate care for PLWD). In a group setting staff could outline their own “cases” of caring for individual patients with dementia, perhaps highlighting the more difficult aspects of communication, and using DEMTEC to discuss, share and evaluate pragmatic alternative approaches.

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The consultation process used to construct and refine DEMTEC involved a small but wide-ranging sample of opinion and experience. The process confers a number of advantages to the toolkit including, perhaps most importantly, the input of PLWD that has hitherto been largely excluded from guides to improving communication. The toolkit contains principles about effective communication and practical advice that is adaptable to individual PLWD in a number of different care and sociocultural environments. The work is based on empirical research pertaining to models of communication, but using language that has been endorsed as appropriate for professionals, PLWD and their families.

Although DEMTEC has been designed to enhance communication with PLWD, it has yet to be field tested in environments which demonstrate that its practical use leads to an objective improvement. Evaluation and dissemination are therefore vital for benefits to be realised. Initial testing of the efficacy of DEMTEC is to be through its evaluation, pre and post intervention, in a number of locations including day centres and long-term specialist residential homes for PLWD in the U.K. Testing for efficacy will involve the analysis of change in health-related quality of life of people living at various stages of dementia. The methodology of this evaluation will involve a more structured approach to interviewing PLWD using dementia-specific quality of life psychometric instruments, for example DEMQOL and DEMQOL-proxy, (Smith *et al.*,2007), as well as objective measures of effective communication between staff and PLWD. Once its efficacy has been demonstrated, versions of DEMTEC will be freely available to all stakeholder groups through web-based dissemination.

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The end product of the empirical work, DEMTEC, will be widely disseminated in a variety of forms tailored to the specific needs of different user groups on a free-to-all-users basis, once it has been tested for efficacy in different contexts. Dissemination will be in the first instance in the UK, but it will then be rolled out internationally. It will include web-hosting with the collaboration of the Alzheimer's Society UK. Hosting will offer interactive communication advice based on the principles and specific considerations included in DEMTEC, and will also provide a mechanism for feedback on practical uses of DEMTEC, and so influence its future development. Other methods of web-based dissemination will be through various channels relating to the international caring community under the auspices of Alzheimer's Disease International and links with dementia care training networks. These international links are currently being explored. DEMTEC is readily translatable into languages other than English, and has already been translated in the Spanish- and Catalan language versions of Young *et al* (2010). We will continue to encourage further translations provided the end products are free-to-users in some form.

One key audience for DEMTEC will be care workers whose first language is not English – a considerable part of the workforce in both North America and the U.K. A version will be produced with a simple, direct writing style suitable for a lower level of English language competency. The 3-level structure of DEMTEC will also allow for the principled discussion of different socioculturally-influenced beliefs about ageing and disability between carers from different backgrounds, facilitating a sharing and cross-fertilisation of attitudes and approaches to care and communication. This should increase the likelihood of international uptake of adapted variants of the toolkit, and make it more relevant to the many non-western people working in care

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environments in North America, the UK and other environments where a large part of the care workforce does not share the primary cultural background of the majority population. For example, the stress in Level 1 on the central importance of acknowledging and supporting individual personhood, agency and empowerment in interaction might be seen as a decidedly ‘western’ orientation, and so may need to be adapted in different national and sociocultural environments, or may be an issue for cross-cultural dialogue in training in multicultural care environments.

In developing this toolkit our work with the spectrum of stakeholders has reinforced in us a sense that, despite progressive cognitive impairment, PLWD can contribute to the development of effective communication strategies in partnership with formal and informal carers. The DEMTEC instrument described here is a representation of real-life experience, best theory and best practice into a tool to empower PLWD and their carers. Training in the use of DEMTEC, and its application to care, is likely to provide highly cost-effective benefits in terms of the improved quality of life, and so, we argue, will be a worthwhile investment even in the highly straightened times facing providers of health and social care across the world.

### **Conflict of interest**

None.

### **Description of Authors’ Roles**

T. Young formulated the research questions. He designed and co-supervised the conduct of the study. He contributed to the drafting and revision of the paper, and produced the final version.

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C. Manthorp formulated the research questions, co-supervised the conduct of the study, and contributed to its design. He contributed to the drafting and revision of the paper.

D. Howells co-supervised the conduct of the study. He contributed to the drafting and revision of the paper.

E. Tullo wrote the first draft of the paper. She contributed to its further drafting and revision.

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## Tables

**Table 1. Criticisms of existing guides to improving communication with PLWD**

- Advice based on conversational analysis of the speech of PLWD seen as too technical to be of use to anyone other than trained speech and language therapists
- Market confusion given the plethora of published and unpublished guides
- Guides lack credibility when not linked to empirical research about communication and dementia
- Advice aimed at non-specialist care and nursing staff seemed patronising, consisting of statements of the obvious
- Advice often given as a “one size fits all” nature, with no attempts to adapt to the individual needs of PLWD
- Guides written for a North-American audience may need to be adapted for other contexts

**Table 2: DEMTEC Dementia Toolkit for Effective Communication: An overview**

<b>Level Three</b>	Five case study scenarios to inform actual communication involving people living with dementia, their care plans, guidance for informal carers and guidance and training for health-care providers.							
↑↑↑↑↑ <i>which guide and inform</i> ↑↑↑↑								
↑	1 Conversation	2 Non-verbal communication/ body language	3 Environmental considerations	4 Anxiety reduction	5 Mindfulness and empathy	6 Understanding behaviours	7 Retaining a sense of self	8 Checking understanding
<b>Level Two</b>	Eight components of good communicative practice, each consisting of a ‘What’ (definition), a ‘Why’ (rationale for inclusion) and a ‘How’ (specific considerations and behaviours).							
↑↑↑↑ <i>which guide and inform</i> ↑↑↑↑↑								
↑	<p><b>Level One</b></p> <p>Beliefs and principles about the importance of communication.</p> <p>The effects of dementia on communication.</p> <p>Approaches to communication which acknowledge personhood and so promote empowerment.</p>							

**Table 3: An example DEMTEC level two component in full**

### **Environmental Considerations**

#### **What are they?**

Here, the environment refers to any setting where communication takes place. These might include a person's home, a hospital, a care home or a physician's office.

#### **Why are they important?**

Communication doesn't occur in a vacuum – things like décor, background noise and distracting activities all impact on communication in informal and formal care environments. The environment for communication involving people living with dementia should help to reinforce and convey meaning. It should not distract or make interaction between people difficult. We all relate different types of communication – for example, an informal chat or a consultation – to different types of environment. Ideally, the environment for communication involving people living with dementia should provide cues and reinforcement – familiarity is helpful and minimizes anxiety. The wrong kind of environment increases distraction, makes communication more difficult, and so increases anxiety.

#### ***Key implications***

- In both home and formal care environments, calmness, a lack of distractions and continuous reinforcement are sound basic principles.
- In the home of a person living with dementia, as far as possible, leave things (décor, furniture, etc) how and where they are – maximize familiarity.
- When communicating, turn off radios, TVs, etc.
- You should be able to sit comfortably facing the person you are speaking to.
- Both space and lighting should be adequate.

In formal care situations:

- For particular types of communication choose, if possible, related 'reinforcing' environments. Formal interviews and consultations should take place in offices, informal chats should take place in lounges, and eating should take

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place in designated dining areas.

- Distracting background noise (from TVs, for example) should be minimized, or it should be possible for people to withdraw from the distraction.
- As far as possible, ‘de-institutionalize’ – have seating in public areas in ‘islands’ for little groups, and try to provide a variety of types of chair (to promote choice and comfort).
- Colour schemes should be calming and ‘non-busy’.

*[end]*