
DEMTEC

Dementia Toolkit for Effective Communication

Version for
health and social care professionals

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1. Background

There is a real need for guidance on effective communication to help everyone touched by dementia – for people living with the condition as well as for those caring for them. The Dementia Toolkit for Effective Communication (DEMTEC) aims to help people to improve communication, in both formal settings (such as care homes and hospitals) and informal settings (their own homes).

DEMTEC has been shaped over an eighteen-month consultation process that has taken place in the UK and elsewhere. The authors have asked for the views, ideas and experiences of people living with dementia and their carers during this consultation. Their contributions have impressed on us that there is an urgent need for such a resource that will both inform and reassure.

The input of professionals from many fields, including care-home managers, speech and language therapists, nurses, psychiatrists and psychologists, have complemented the input of people living with dementia and their carers. We have also drawn on the growing body of research evidence in the theoretical and professional literatures.

DEMTEC pulls together all the elements gathered during the consultation process and aims to enable people to use simple, accessible strategies with which to improve communication.

2. Framework and Rationale

2.1 The framework

DEMTEC has a three-level framework:

Level One:

A statement of beliefs and principles that provides the theoretical foundation. This informs Level Two.

Level Two:

DEMTEC components, consisting of:

- The 'What' – a definition of the component (for example, what do we mean by 'environmental factors'?).
- The 'Why' – a rationale for including the component in DEMTEC (for example, the impacts of environmental factors on communication involving people living with dementia).
- The 'How' – implications for, and guidance on, effective communication practices relating to the component.

Level Two informs Level Three.

Level Three:

Actual communication involving people living with dementia, which can be applied to:

- individual care plans for people living with dementia
- carer guidance and training adaptable for different contexts for both the informal and formal carer

Figure 1., below, illustrates the overall shape and content of DEMTEC.

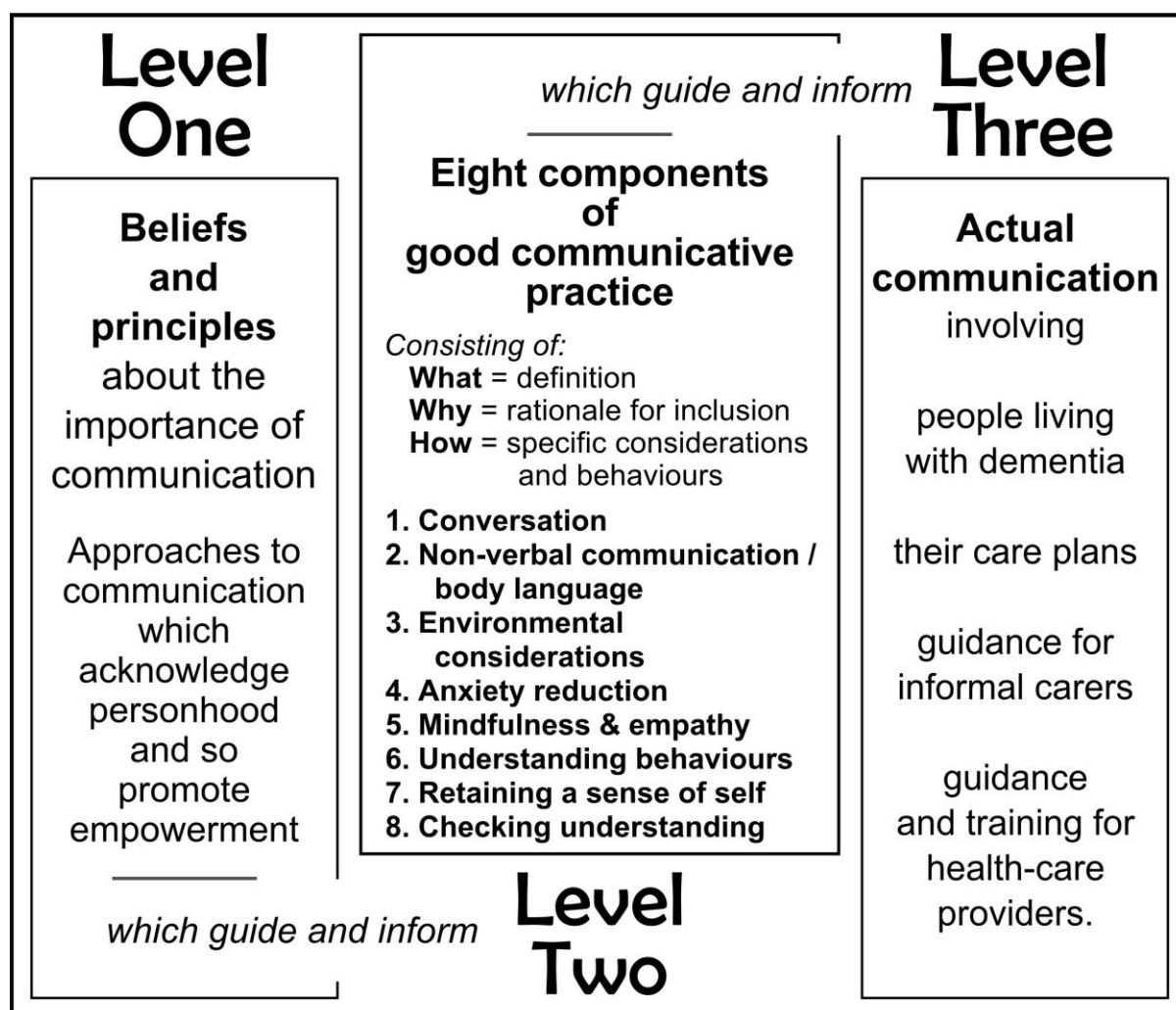


Figure 1. The structure of DEMTEC

2.2 Rationale

- There is considerable academic literature relating to communication practices involving people living with dementia, but the guidance arising from this literature rarely informs actual interaction between people living with dementia and their carers.

- There are numerous examples of good practice in care, and DEMTEC facilitates the drawing together and dissemination of these practices.
- This three-level framework makes explicit to all involved what is believed to be best practice, and the principles and beliefs which underlie this best practice.
- The framework also allows for principled discussion of best-communication practices and for their adaption, over time, and to different socio-cultural contexts.

3. DEMTEC Level One:

Underlying Beliefs and Principles

DEMTEC is not produced with the intention of being a set of hard and fast 'rules' that are set in stone. It is designed to be a dynamic tool, adaptable to different contexts and to the needs of individuals, which, of course, vary enormously. That said, it is possible to draw up a statement of agreed principles which would underlie, guide and inform good communicative practice.

DEMTEC is therefore based on the following:

- what we know about the nature and importance of communication
- beliefs about the effects of dementia on communication
- beliefs about the communicative needs of people living with dementia

3.1 The nature and importance of communication

Any communication between people has two main, strongly related purposes:

- the sharing of meaning
- the fostering of social connections between people

Communication is a basic human need and, as such, making it as effective as possible should be a basic human right. Communication enables us to project our identity and to have our identity confirmed. Communication can be seen as a process, as well as an act, or series of acts.

Briefly, seen as a process, it consists of:

- communicators
- the message (what people are 'trying to say')
- the medium (presentational: the voice, face, body; representational: words, pictures, architecture; or mechanical: TV, computer, telephone)
- the channel (vocal, gestural/visual, chemical/olfactory, tactile)
- a code (a system of meaning shared by a group, for example, a language)

- noise (factors tending to blur the message, for example, misunderstandings arising from 'misreading' body language, as well as background environmental distracters like loud music)
- feedback (things which help the message sender to be able to judge whether they have been understood)
- context (who is communicating with whom, when, where and with what presuppositions and expectations).

3.2 The effects of dementia on communication

People living with dementia may:

- be confused
- experience a sense of loss of purpose and identity
- feel uncomfortable exploring their diminished competences
- be anxious about their condition and its possible progress

As a consequence, they may:

- have difficulty following rapid or complex speech
- attempt to convey meaning in ways that are discontinuous and lacking in logical structure, but may express underlying concerns metaphorically
- have difficulty encoding or decoding meaning
- be especially susceptible to 'noise', be it environmental, socio-cultural or situational
- find some behaviours unhelpful in others' attempts to communicate – for example, a perceived patronizing tone or a too-rapid action accompanying an explanation.

3.3 The communicative needs of people living with dementia

We believe that people with dementia can be:

- agentive, i.e. able to be in control of their own lives and circumstances as far as possible
- offered support in continuing to 'own' a clear idea of themselves as individuals, and of themselves in a particular socio-cultural context
- helped to feel less anxious
- aided in their attempts to negotiate and maintain a sense of self and of personal and social identity
- assisted in their attempts to communicate effectively with others
- helped to retain and regain competences
- approached and treated in such a way that their dignity and freedom of choice are reinforced and supported.

Dementia can profoundly affect a person's ability to communicate effectively. People living with dementia are, nevertheless, individuals with communicative needs. Addressing these needs in a clear and principled manner, which fully acknowledges individual 'personhood', is a key element in any positive encounter between people.

Overall, a person-centred approach to communication between carers and those living with dementia should have the effect of initiating a virtuous circle of improving communication. With this, the recognition of a person's individual agency by a carer both increases the individual's sense of competence and improves the quality of social interaction for both parties. These principles are at the heart of DEMTEC.

4. DEMTEC: Level Two

Advice and Guidance

In this section, we will define, explain and give detailed advice and guidance on each of the Level Two components of DEMTEC.

The eight components of Level Two are:

- 4.1 Conversation**
- 4.2 Non-verbal communication / body language**
- 4.3 Environmental considerations**
- 4.4 Anxiety reduction**
- 4.5 Mindfulness and empathy**
- 4.6 Understanding behaviours**
- 4.7 Retaining a sense of self**
- 4.8 Checking understanding**

4.1 Conversation

What is it?

Conversation is where most communicative 'give and take' happens. As such, it is absolutely central to exchanging meaning, to helping people keep a sense of themselves and what is happening around them, and to fully participating in life. We can do certain things to make conversation more likely to happen in a mutually satisfactory way both for people living with dementia and for those around them.

Why is it important?

Studies have shown that most people living with dementia engage less in conversation as their illness progresses. This may be due to problems experienced by the person living with dementia – their attention may wander, they may speak 'off

subject', or they may make more (or less) of a contribution to conversation than is considered normal.

It may also be because others find it difficult to know how to interact with those living with dementia and tend to limit their conversation with them to very instrumental, task-based subject matter. Certain relatively simple strategies can be employed to make conversation more satisfying for both parties.

Key implications

- Conversation *is* caring. You aren't just chatting, you are acknowledging someone as a person.
- Always introduce yourself if you haven't met before, or if you think they don't recognize you.
- Use whatever a person living with dementia is doing or saying to give you a starting point for a conversation.
- Conversational 'tempo' is really important. A person living with dementia will probably need more time to respond, so allow them this time.
- Touching someone could be a good signal that you want to start a conversation.
- If the person doesn't understand, think of a simpler way to say what you want to say.
- If the conversation contains information that you know isn't right, or that you don't understand, ask them a question to try to clear things up.
- During the conversation, watch for non-verbal communication ('body language') that is telling you something different from the topic of the conversation.
- To check that they are following you, use words that the person has used, or use words that have related meanings. Give them as many related cues and clues as possible to help them to understand what you are saying.
- Pictures or pointing to something for reference may be useful in helping the conversation along.
- Try using everyday tasks to get a conversation going. For example, 'Would you like chicken or fish for lunch today? Which do you like best?'
- Keep a sense of humour!
- More or less everyone likes to gossip, so don't restrict the topics of conversation to the neutral (such as the weather), or the instrumental (for example, getting everyday care tasks done).

When speaking:

- If the conversation relates to tasks or instructions, remember the acronym **KISS**: Keep It Short and Simple.
- Make sure you have got the person's attention.
- Give directions with key words at the end.
- Speak slowly and clearly.
- Discuss one idea at a time.

- Avoid negative questions (such as ‘Don’t you want coffee?’)
- Don’t be too ready with stock answers.

When listening:

- It is important to give the person your attention.
- Try to be aware that you might have distractions, too, be they emotions or concerns or your own.
- Listen actively ‘with all your senses’ to pick up cues and clues.
- Be aware of different listening styles. There may be gender or cultural issues which make you, or the person you are speaking to, more or less likely to listen attentively.
- Focus on the positives – what a person can do, rather than what they can’t.
- Make the person feel that you have valued talking with them by making a positive comment at the end of the conversation.

4.2 Non-verbal communication (NVC)

What is it?

NVC involves using the face or body, consciously or otherwise, to convey meaning. It consists of a number of elements, which include:

- eye contact and eye movement
- gaze (direction and intensity)
- facial expressions
- touch
- gestures with the hands
- body posture and orientation (for example, sitting up straight, or facing a person you are speaking to)
- use of the voice (tone, pitch, volume, intonation, speed)
- vocalization (‘ums and ahs’, etc)
- the way you dress and general bodily adornment

Why is it important?

NVC often carries as much information as verbal communication, and can have a profound effect on how we see, and are seen by, others. The ability to ‘read’ NVC tends to last longer than the ability to understand speech, perhaps because it precedes it in human development.

Impairment of hearing in older people living with dementia (a common problem that carers sometimes make too little effort to relieve or accommodate) can put an even greater premium on effective use of NVC.

Decoding facial expressions carries more meaning for people living with dementia. Even people who have lost the ability to speak or to apparently understand speech

can respond to facial expressions. Similarly, gesture can serve as a useful reinforcement to speech, and tone of voice can be especially reassuring (or threatening).

Key implications

- Be aware that gentle touch is very helpful in reassuring people and reinforcing meaning.
- You should make eye contact whenever possible. It can be reassuring to people who are having trouble understanding speech or intention.
- Face-to-face, non-threatening positions are good for promoting understanding.
- You should also sit close to people living with dementia, and sit at the same level (don't 'loom').
- Try to avoid distracting hand movements when speaking.
- Remember that different gestures may have different meanings to people from different socio-cultural backgrounds, so try to use those which you know are meaningful and appropriate.
- Be consistent in your body language – use similar gestures to mean similar things.
- Be aware of any possible cultural constraints – how appropriate is touch, and is gender an issue, for example?

4.3 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 doctor'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 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’.

4.4 Anxiety reduction

What is it?

Anxiety is a state of excessive concern for an apparently innocent situation. It is common in people living with dementia, particularly in the earlier stages, where it can be the first indication of problems. How carers engage with the person is a key feature in provoking or reducing that anxiety. People living with dementia usually respond favourably to carers who use communication techniques that are tailored to the situation and to the individual, and who try to understand and communicate.

Why is it important?

As with us all, anxiety in people living with dementia is associated with a lower quality of life. The anxiety may result from specific concerns associated with the condition such as forgetfulness, or it can be ‘free-floating’, latching onto personal and environmental concerns, or it can have no obvious triggers at all.

Anxiety can be particularly tormenting for people who realize that their memory is getting worse, and who are apprehensive about the consequences of the disease.

Helping people to identify anxiety and to interact appropriately will improve the quality of life of both parties, and should help reduce care-giver burden and burnout. As people living with dementia become progressively more impaired they may

sometimes worry less about their cognitive and behavioural deficits and become more contented, and so may become generally less anxious.

Key implications

- Speak clearly in a conducive environment.
- Make reassuring gestures (for example, holding someone's hand).
- Avoid behaviours that might be interpreted as aggressive (for example, making sudden movements or interactions without the reassurance of an accompanying description of the process you are about to carry out).
- Using a calm tone, humour and a friendly smile or gesture is likely to be helpful.

4.5 Mindfulness and empathy

What are they?

Mindfulness and empathy represent a commitment to finding meaning in confused speech or behaviour through your understanding of the individual, their motives and their circumstances. They constitute having an openness to 'clues' to meaning in speech, behaviour and their linkage.

This might involve being open to gestures that suggest distress or need, or repetitions that suggest that something is important, or fractured or unusual language that might be hinting at a particular target, rather like a cryptic crossword clue.

Why are they important?

Although it is often difficult (and sometimes impossible) to find meaning in confused speech, the alternative of assuming that all speech from people living with dementia or advanced dementia is meaningless isolates and alienates the individual, undermining their self-confidence and has a self-fulfilling quality.

A mutually agreed consensus on meaning can often be arrived at – even if the main focus of concern may shift for the individual living with dementia. A sense of communication is a validating and comforting experience for both parties. As with everyone, people living with dementia have the right to have reasonable desires satisfied where possible.

Key implications

- Try to relax! Allow yourself to go for instinctive 'feelings' for what a person might mean.
- Bring an understanding of the individual to this process – for example, someone who is frequently hungry may often be referring to meals; someone who hates being confined may often be trying to find ways to express a desire to leave; a car mechanic might be given to lying under tables, etc.

- Bring an awareness of environmental and physical circumstances to exchanges – on hot days people will often want to ask for a drink!
- Time of day may also be an issue – some of us aren't 'morning people', and some people with dementia have difficulty knowing what time of day it is.
- Those living with dementia may not adhere to cultural norms in many aspects of behaviour and their needs may best be met through a flexible approach and respecting their individual wishes.
- Be aware of people's history and preferences, and listen for key words and try to be receptive to what the person means.
- Problems apart from dementia might make it difficult for a person to understand, or be understood. For example, their eyesight, hearing or dentures may cause them problems. Make sure these are tested, and that glasses and hearing aids, if worn, work, and that dentures fit properly.

4.6 Understanding behaviours

What is it?

Communication is used to transmit ideas and influence people. Communication between a person living with dementia and others risks breaking down because of differences in their understanding of what is meant. Carers can inadvertently inflame a situation when the wrong cues have been picked up or when their desires are unwittingly in conflict.

Recognizing common difficulties and developing appropriate responses helps to make everyone involved aware of possible misunderstandings so that they can be addressed.

Why is it important?

'Behavioural disturbance' in a person living with dementia can be thought of as an expression of their 'unmet needs'. It might look incoherent or aggressive to those not familiar with such methods of interaction, and might result in inappropriate behaviours being reflected back at the person living with dementia. Such 'unhelpful behaviours' on the part of well-intentioned carers can be reduced through engagement in different ways.

Reducing behavioural disturbance in people living with dementia is vital to improving their quality of life: it will help to reduce institutionalization and lower the need for potentially harmful psychotropic medications. Care-giver skill and improved social interaction have been shown to help this to happen. A common example of behavioural disturbance is aggression towards others, which often indicates fear or frustration. This can be helped by leading the person concerned into a calmer or more interesting environment.

Key implications

- Always try to understand, using whatever clues are available.
- Listen carefully, and try to understand by drawing on your knowledge of the whole person.
- Try to avoid being overly judgemental of 'bad' behaviour, and also try not to take it personally.
- Consider if something you are doing or saying might be the cause of the distress.
- Try to balance the needs of everyone involved. Safety (for example, with gas) is an issue, but so is personal freedom for the person living with dementia.
- Be aware of the possible cultural reasons behind behaviour. What is normal for them? What do they expect to happen? What boundaries are there (in relation to touch, or to gender, for example)?
- Be creative and flexible in the solutions you offer. Think of alternatives: try to work around the problems of the person living with dementia.
- Avoid escalating bad situations. Don't force issues.
- Is there an unmet need? Offer suggestions.
- Take your time. Allow the person as much time and space as possible.

4.7 Retaining a sense of self

What is it?

Giving those living with dementia prompts and clues that help them to remember who they are, what they are doing and why they are doing it.

Why is it important?

People living with the later stages of dementia often begin to lose their sense of identity and prompts about name and context are useful reminders. Making clear what is happening and why helps people to understand what is going on and reduces anxiety. It also provides a context that may help make an activity easier and more meaningful. Remember also that people change – allow for this change, and for growth in the individual.

Key Implications

- Get to know as much as possible about the individual. In a formal care setting, make the effort to learn about their life history, their preferences, who their significant others are, whether they like to be called by their first name or by a title, such as Mrs or Mr, etc.
- Personalize the space around those living with dementia. In their own homes, leave things as they are, as far as possible. In care environments, allow for personal objects, 'reminiscence' items and other things associated with their past and present life to be around them – make things as 'homely' as possible.

- Try to strike a balance between ‘preservation’ and ‘new identity’. Some of the changes that may happen with dementia are not necessarily negative. For example, people might be less inhibited and want to have fun!
- All activities, even the most functional, can have a personalizing and reinforcing quality – call people by their names, tell them what is happening, and why.

4.8 Checking understanding

What is it?

Concept checking is making sure that your understanding is accurate. For example, you might ask someone ‘Did you say that you would like a second helping of salad?’ Concept checking can be particularly helpful for people living with dementia who may seem to speak ‘off subject’, or use incorrect words, sentences or grammar that may nonetheless give strong clues about what they mean, and these can be checked with them.

Why is it important?

Concept checking is important because it often makes it easier to get to a person’s intention and meaning. It also shows the person living with dementia that their struggles to communicate are being taken seriously and that a joint effort may help to overcome barriers.

Key Implications

- Keep your sentences short, clear and concise, and use simple words.
- Repeat an idea in a sentence using different words.
- Use visuals – pictures, point at objects, write things down.
- Try removing other distractions, such as music, when you check things.
- Patience and positive reinforcement are good basic principles.
- If in doubt, check.

5. DEMTEC: Level Three

Case Studies

This section shows how DEMTEC can be applied to real-life situations, which constitutes Level Three of the toolkit.

Everyone’s experience of dementia is unique, but we have chosen these three case studies as illustrations of widely-experienced challenges people face at different stages of the condition. The scenarios describing the experiences follow a general pattern of early, mid and late stage dementia.

We have highlighted in each case study how DEMTEC is relevant, and might be applied. The advice in each scenario illustrates the relationship between Level One and Level Two of DEMTEC. So in each instance the underlying belief in a person-centred approach to communication, and in the need to support dignity and agency for people living with dementia, is related to specific guidance and advice on communication strategies and considerations which are informed by these beliefs.

In each instance we have highlighted Level Two components that may be particularly relevant, and have tried to show how each of the eight components interact, and are relevant. You may be able to think of other relevant components for each case study as you read.

5.1 Jack

Jack is a 68-year-old man who worked in the local steel works for all of his working life. Now retired, he still lives happily with his wife of 43 years.

Jack reports having felt increasingly absent-minded over the past few years but attributes this to 'old age'. He has coped well and enjoyed life for many years with his regular routine of gardening and visiting the local pub two nights per week. However, his wife is worried by his worsening memory. He keeps losing his wallet and glasses and forgetting the names of their grandchildren and great-grandchildren, whom he sees often.

Concerns were raised to their GP four weeks ago when he was suffering from a chest infection and became grossly disorientated in time and place. Jack seemed to think that he was still working, asked to go home when he was in his own front room and misidentified his wife as his mother, who has been dead for many years. This crisis has resolved but there has been a formal diagnosis of dementia, and now Jack is worried that he is 'going mad'. He remembers his mother developing dementia and requiring hospital care over a long period. He feels that this was a very undignified and depressing existence and he would rather be 'put down, like a dog' than go through the same.

Jack is finding it difficult to settle back into his normal routine and now constantly follows his wife around the house, seeking reassurance and refusing to be left alone. His wife is finding this hard to cope with.

Jack finds himself in a position that will be familiar to people living with dementia and their families – and in a position that is much less familiar to most formal carers.

People working in residential care, for example, who are used to helping people who need extensive support and physical care and who often have little remaining insight

into their situations, need to stretch their imaginations to appreciate both the terrifying nature of a diagnosis of dementia and the potential that remains for a full and enjoyable life.

The toolkit is designed to encourage people living with dementia, together with formal and informal carers, to keep this potential at the front of their minds.

Jack is facing very real changes to his life, and his anxieties are made worse by his sense of his mother's suffering. It is entirely natural to have a sense of loss and to be frightened, depressed and angry in his situation. Anyone speaking to Jack about his living with dementia needs to recognise the grief and anxiety which arises from his reactions to his mother's experience. But they also need to recognise that he is in no sense less of a person.

One of the most inspiring developments for people living with dementia in the UK and elsewhere over the past 10 to 15 years has been how people have begun to accept the illness they are living with and to find ways to combat it.

A diagnosis of dementia is no longer something to be ashamed of, something too terrifying to be discussed, an instant ticket to the 'loony bin'. It is a condition that can be rationally analysed and adjusted to: self-help groups, in particular, have contributed to people and families fighting their way out of the crippling depression that so often accompanied a diagnosis of dementia and finding ways to make the most out of their lives.

Applications of the toolkit

What are the practical applications of the toolkit for Jack and his family?

Clearly, consideration of a number of areas from the toolkit would be helpful in this context. Putting yourself in his shoes, and listening skills and speaking skills spring immediately to mind.

It is not surprising that Jack is anxious, and that this puts a lot of strain on Jack and his wife. It is natural to be frightened and to dwell on negative experiences or stereotypes. It is very difficult for carers to offer reassurance about a condition that they may themselves find overwhelming and frightening, and about which they may know very little.

In this case, as in most others, knowledge is power, and reaching out for help is natural. Try the following:

- Finding self-help groups in the area, both those offering peer support to people living with dementia and those geared around the needs of carers.
- Contacting special interest organisations like Age UK, <http://www.ageuk.org.uk>, (formerly Age Concern and Help the Aged) Age Concern, Help the Aged and the

Alzheimer's Society, <http://alzheimers.org.uk>, or more specialised bodies such as the Lewey Body dementia group. These groups have a lot of experience and can be very helpful.

- Contacting Admiral Nurses, <http://www.dementiauk.org>, if they are available, a group of nurses selected for their ability to work with people living with dementia and their carers.
- Seeking out the Residents and Carers Association, the funkiest, stroppiest and most likeable large pressure group in the UK.
- Reading some of the wide literature available and the advice available on the web.
- Looking for formal counselling for people living with dementia where it is available.
- Talking to friends.
- And, always and most importantly, talking to one another. People living with dementia and their carers need to communicate!

In practical terms it is also worth considering what will help Jack settle down.

As with anyone else facing anxiety, the re-establishment of routines is often helpful. Encouraging and enabling Jack to re-engage with his garden and his friends in his local pub is the most natural place to begin. Help from friends and family may be necessary and should be unashamedly asked. Jack's wife also needs to make sure that she has made space for herself and her own needs.

Is there a case for talking to Jack directly about his memories of his mother and her difficulties with dementia? It depends on circumstances and on the individual. Some people might find it helpful to re-discuss a traumatic episode or perhaps to begin looking at present day alternatives to the almost universally relentlessly grim institutions to which people living with dementia were once recommended. Others will be more comfortable finding the more positive aspects of their own position and re-establishing a balanced life, choosing if and when to look at previous experiences or options for the future.

Suggesting options and allowing people to explore them as they wish is the most practical and helpful approach.

Returning to the moment of diagnosis of dementia discussed earlier, it is worth pointing out that a significant number of people actually found this a positive experience. Several individuals, people living with dementia and family members in particular, told us about having had the experience of finding themselves in a position where their lives were becoming difficult to manage. They were struggling with their jobs or with everyday tasks and had no idea why. In many cases there was considerable strain on relationships and in some instances there was blame and breakdown.

In such instances a diagnosis of dementia provided an explanation and a sense of a degree of liberation, a basis from which progress could be made. Many people talked of the positive impact of preventative drugs like Aricept on their lives – and more about the support they felt as people living with dementia or carers from contact with self help groups, where problems and solutions could be discussed and shared, where shared experiences and companionship were available, where people could openly express fear, anger, acceptance – and where people were able to laugh at their experiences. Medical and social care professionals have a lot to gain from talking to such groups about their experiences – and considering how they can change their approaches as a result.

5.2 Frank

Frank is a 70-year-old man who previously worked as an office clerk and has been living with his daughter since the death of his wife three years ago.

It became obvious following his wife's death that Frank had considerable memory problems that his wife had been covering up. He has since been diagnosed with dementia and has great difficulty with dressing (frequently wearing inappropriate clothing for the weather or dressing in the wrong order, e.g. trying to put underwear over his trousers). He is a very proud man and became difficult or even aggressive when his daughter tried to help. Despite being a generally well-groomed man he was also refusing to undress or wash, apparently unaware of any personal hygiene issues and resentful of any attempts to discuss this with him. A care package was introduced to help him with personal care in the mornings and this has been successful for the most part, although he can refuse to co-operate at times.

Frank mostly stays in the house, in a small, dark living room, watching the television while his daughter goes to work during office hours. He is able to make himself a cup of tea with biscuits but little else. He usually does not leave the house. However, as a precaution his daughter has begun locking him in while she goes to work. She has done this since an episode where he left the house during the day and was picked up by the police, in a very anxious and dishevelled state.

Otherwise Frank's apparent interests in life are increasingly limited. He very rarely initiates any conversations and usually gives only monosyllabic answers to questions. He does not express any wishes, hopes or desires, and time spent with his daughter is most often characterised by long periods of silence.

As a case study, Frank's behaviour and difficulties in managing suggest that he is in the early to middle stages of dementia, and that he is in difficulties.

His lifestyle is not good for him – a reducing set of options over his day-to-day routine. Living on biscuits, tea and television in a small dark room, barely conversing, unable to go out – it sounds like a prison sentence for the crime of being ill. It carries a strong sense of depression with it – and it is an all-too-familiar scenario.

Dementia is an illness where links with depression are increasingly acknowledged but still not fully explored and explained. It is not the least surprising that some people diagnosed with dementia (or filled with dread at their own cognitive losses and increasing difficulties with managing the world) should often go through a period of depression. Figures for suicide in early stage dementia are appallingly high. The relationship between depression and dementia, however, is not straightforward: it is easy to mistake severe and chronic yet treatable depression for dementia – and depression is much more common in old age than we used to acknowledge.

Carers need to be aware of this. But the link is more complex: depression may contribute to dementia. If you are apathetic and listless you give yourself little stimulation and it is easier to fall into problems – so depression and dementia may feed one another in complex ways.

While she was alive, Frank's wife will have felt that she was helping him by covering for his memory losses, and will have done so out of an understandable and loving instinct to help. But it is horribly common after the death of a spouse to see other family members take over the lives of people living with the early stages of dementia, reducing that person to an unnecessary amount of dependence – a situation that often happens in residential and nursing care, too.

People living with dementia may well find some tasks frustrating and difficult and will be very grateful for help. But if you do everything for them, you take away their ability to do it for themselves, and if you cover up memory loss you compound a sense that it is something to be ashamed of and hidden away rather than a problem to be confronted and managed where possible.

It is vital that people are given as much control over their own lives as possible. Many people with dementia and their partners manage to find humour in their day-to-day experience of dementia – and it is clear that this is an option that often helps people feel more dignified, human and strong. There is clearly a place for putting yourself in their shoes here – for carers to think about what might help them under similar circumstances, to try to find meaning in confused or unhelpful behaviour.

More than anything else, Frank's behaviour can be read as suggesting an underlying anxiety. He has withdrawn from the world and is too uncomfortable with his own position and with his relationship with the world to be able to respond positively to his daughter's attempts to help him dress.

Applications for the toolkit

There are strategies, detailed in DEMTEC, that can help with people living with dementia by acknowledging, managing and hopefully reducing this anxiety.

It is almost always better not to make a big issue of small failures, for example, and to think about trying to reduce people's anxiety. If someone who you love and who you know takes pride in their appearance dresses themselves in a way that makes them look ridiculous, it is easy to respond by chiding or to overreact generally. It may be much better to make a gentle comment, to lead people back to their wardrobe and leave them with or offer a selection of more appropriate clothing. After all, in the end, of course, an eccentric choice of clothing is not the end of the world.

Helping to manage poor personal hygiene can be more problematic and is quite a common issue. Some people living with dementia may be less sensitive to the reactions of others and less inclined to go through the increasingly difficult process of dressing, undressing and managing a bath or shower safely.

A reaction of manifest irritation or disgust is only going to provoke hostility or more anxiety. It is much more helpful to think about anxiety reduction again – to draw a bath for the individual, to show them to the bathroom and to try to ensure that bathing is a relaxing experience – with privacy, soft light, bubble bath, the radio on or whatever – and to accept that there may be occasions when this will not be enough to encourage people.

Carers may have to accept that the strategy has not worked and try again later – or see if more formal carers, visiting 'home care' staff for example, can use a kind of residual 'medical-type' authority to persuade the person living with dementia that they are being helped rather than bullied.

There are broader issues here. Frank's daughter has selflessly stepped in to help Frank after his wife's death – but unsurprisingly this can often lead to a sense of resentment and of being trapped, at a conscious or unconscious level. Or it may simply not be the best arrangement – not every father and daughter can live together happily even without the complicating factor of a debilitating illness and there is nothing to be ashamed of in that.

It doesn't seem to have worked out well, anyway. Frank has reduced himself to monosyllabic replies, which is no doubt frustrating for his daughter and which does him no favours in terms of keeping his own sense of himself as a person, maintaining his social skills, contact with the world and interest in it. It would surely be sensible to look for social contacts to reduce isolation – perhaps contact with old friends in a familiar social situation like a pub, café or club, or organised activities in a day centre. For almost everyone, social contact is a necessity.

Having said that, for some people living with dementia at some stages verbal contact becomes very difficult – and it is possible that Frank has reached that stage. Nonverbal contact can assume far greater importance at this stage – approaching people in a reassuring way, holding their hand, hugs and smiles – these are all approaches that give a sense of contact and of life shared which are understood and helpful long after people can no longer respond verbally.

The strategy of locking Frank in needs comment. It may be an understandable reaction to potential dangers but it is clearly a mistake. In health and safety terms it is unacceptable (what happens if there is a fire?), but it also reduces Frank's world to a prison and deprives him of a contact with the world that his behaviour suggests he needs.

Again, socialising with friends or visiting a day centre might help – but at this stage Frank and his daughter perhaps need to be thinking about the presence of a carer through the day or a move to an environment like a residential or nursing home where Frank's life can centre around contact with others and the world around him again.

One of the things a good residential care environment will certainly do is to look for Frank's interests and to try to cater for them.

The authors remember hearing the story of a clerk in residential care who had worked her whole life in accountancy, adding figures. She had come into residential care as she had become unable to manage for herself but was clearly aimless, unhappy and frustrated.

Staff in the home talked to her and to relatives and had the bright idea of giving her columns of figures in the format she was used to and an adding machine. She would sit happily for long periods working through this task, conscious of feeling that she was useful. At roughly 5 o'clock every evening she would stop. Staff learnt that she had always unwound at home with a gin and tonic and began to provide this, rewarded almost always with a genuinely happy smile and a toast. This really was putting good care into practice.

5.3 Patricia

Patricia is a 72-year-old lady who worked as a telephonist before taking early retirement with multiple physical problems.

These problems restricted her mobility. Combined with a poor diet and a lifetime of heavy smoking, they placed her at high risk of arterial disease. She suffered

numerous strokes that severely affected her physical health, eventually becoming bed-bound, incontinent and dependent on assistance for all activities of daily living. This also increasingly affected her ability to both understand what had been said to her and to communicate back to people in a way they could understand. This is frustrating for both her and the carers at the nursing home.

She increasingly found that the effort to communicate was too much for her, partly because the time put aside for social interaction with the staff was limited by the rolling routine of physical care and everyone always seemed in a rush. She has become much more isolated and withdrawn. Relatives began to visit much less frequently because it is so difficult to hold any kind of conversation – or even to get any signs of recognition or pleasure. When she was more communicative Patricia expressed a desire to remain in her sparsely decorated room rather than spend time in communal areas and this remains the pattern of her day.

Patricia shows little interest in a small television left switched on in the corner of the room and now spends more time looking at the ceiling or shouting out. The shouting is distressing and seems to express discomfort, anxiety and a need for attention. If staff go to help, however, Patricia does not appear to know why she is shouting. No physical cause for the behaviour could be ascertained by staff or by visiting medical practitioners.

Patricia now often resists being changed when her incontinence pad is soiled, resulting in her spending long amounts of time in the pad. Antidepressants to help her mood do not appear to help and a trial use of sedatives simply made her more agitated or very drowsy.

Carers are becoming increasingly despondent at their apparent inability to help Patricia. Working with her has become increasingly stressful and she is sometimes openly discussed as 'a difficult patient' between carers offering support to each other.

Patricia represents a case study of someone moving towards living with the later stages of dementia, which in most people is the product of the interaction of strokes, lifestyle factors and Alzheimer's or other syndromes. Most formal carers and some informal carers will have had the experience of working with people in the very late and most saddening stages of dementia, where verbal communication often disappears altogether and where communication of any kind may seem virtually impossible in the face of an apathetic or depressed silence, broken only by restlessness, shouting and distressed or resistive behaviours.

It is a state that people in early stage dementia like Jack (with his experience of his mother's late stage dementia) fear most.

At the moment the medical profession has little in its armoury that is genuinely helpful in the context of later stage dementia: we can use drugs to prolong life but we can do little to improve its quality through, say, increasing insight. On the other hand, drugs and other treatments can also be used to help with the physical problems that are frequently associated with this stage of dementia, like problems with bowels or pressure sores.

Attempts can be and frequently are made to reduce anxiety or depression, as they have been with Patricia. They may help in some instances but they can also do more harm than good, and the use of anti-psychotic drugs in particular often (arguably) owes more to everyone involved wanting to feel they are doing something helpful (or to a less laudable desire to reduce and manage 'difficult' behaviour) than to a real contribution to the welfare of the person being treated.

Applications for the toolkit

How does the toolkit apply in this context, where apathy and/or depression and cognitive loss make communication so difficult? Can it be at all helpful?

What the toolkit tries to bring to everyone with experience of working with people living with the later stages of dementia is a sense of their personhood and of our shared need to do all we can to respect, preserve and cherish a sense of everyone as an individual.

It used to be (and perhaps still too often is) common practice for the ill-informed to refer to people in the later stages of dementia as being 'like babies' or even as 'vegetables'. These are twisted, grotesque and unhelpful caricatures of reality. Babies have not lived long and meaningful lives, or experienced the range of terrifying losses associated with later stage dementia. Vegetables do not feel pain, depression or the desire and ability to find some way – any way – of expressing these emotions.

Better analogies would be to say that people with later stage dementia are like people in prison or people dying with clouded consciousness, retaining their human rights, needing our contact, entitled to our respect and love.

We owe it to ourselves, too, to treat people in prison or who are dying and unable to respond with respect: it diminishes us as human beings not to do all we can to retain dignity and decency as frameworks, not to retreat into indifference or mechanical performance of care tasks. To have held the hand of a person as they die will, one hopes, be a comfort to them. However distressing it may be it is no less a comfort and an affirmation of humanity for ourselves, as carers, friends or family.

Some elements of the toolkit may be applicable to Patricia's illness as it stands but may be less so if her illness progresses, though none are without use. For example,

while conversation as such may be difficult to impossible, listening skills are clearly necessary when people are able to formulate sentences that we may be able to decode or help people reformulate. They are less useful when people living with later stage dementia are unable to formulate sentences or even words – but in the broadest sense their usefulness remains.

What is causing Patricia to shout, for example? Is it an expression of anxiety or loneliness indicating that whatever her previous desire to stay alone in her room she now needs human contact? Is it an attempt to communicate pain or anguish or a desire simply to express these feelings, which should be respected and responded to?

Most components of the toolkit still have some usefulness. Consideration of the environment is clearly important. For example, Patricia may have moved to a stage where she now needs something more than the comfort of isolation in her room that she chose some time ago. She might move later to a stage where the television turned on in the corner becomes an irritating and bewildering distraction – some people come to truly want peace and quiet.

Alternatively she and we might find that she responds with delight to the kind sensorily stimulating environment provided by ‘snoozelum’ equipment – flashing lights, tactile experiences, etc. – or to something as simple as a leisurely warm bath.

There is also much to be said for involving people living with the later stages of dementia in the preparation of meals. Even people who can no longer help to peel a potato or dry a plate may respond with pleasure to the familiar activities, smells and noises associated with cooking.

In the context of people living with later stage dementia, beyond the simple but absolutely necessary recognition of a person as a person, the two elements of the toolkit likely to prove most helpful are body language and trying to help her keep a sense of self.

A clear focus on the possibilities and possible problems of body language become more and more important if people are having increasing problems with language. Some researchers have found the use of flashcards helpful in reaching through to people living with late stage dementia. The simple act of hugging someone or of holding their hand can be of immense comfort to people who have little apparent ability to communicate left – a very real reinforcement of personhood. Similarly, think about how we approach individuals when we are going to sit down with them – or how to carry out a necessary care task like changing a soiled pad.

Just as people living with early stage dementia may need carefully-paced speaking from a carer, and extra time to come up with responses, so people living with later

stage dementia will need time to appreciate what the carer's approaches to them may mean – or what their intentions are.

Imagine how it might feel if you were having problems with communication, bewildered and frightened in a residential or hospital environment. Further imagine that a nurse or carer comes up to you in a whirlwind rush and begins removing your clothing with at best a perfunctory (and incomprehensible) explanation. It would be no surprise to find yourself lashing out indignantly. If, however, you are approached by someone who sits with you and takes some time to reassure you, through touch and through communicating their own calm and helpful intentions it would clearly be a less distressing experience. Tone of voice perhaps becomes really important.

This kind of approach shows that carers recognise that people even in the later stages of dementia may be able to appreciate and occasionally respond to a continuing, soothing verbal explanation of what tasks are being carried out and why. It may help to keep self-respect and a sense of control, through co-operation (or resistance, which should be respected too!). Anything that stops people who are living with later stage dementia feeling as if they are being treated as things being done to (as part of a sausage machine of care practices) restores dignity, prevents depression and gives some quality of life.

An inspiring example of the allowance of agentic response and reinforcement of personhood and identity in the context of later stage dementia was given to the authors by a well known psycho-geriatrician. She was living with early stage dementia herself, and understood the possible progress of her illness. She told us about one of the first self-help groups for people living with dementia, a group that had got together in the United States and to which she had been a regular visitor as a supportive medical practitioner long before her own illness and diagnosis.

She had visited the group over a lengthy period and had watched the energetic founder member of the group slip through stages of dementia that meant he found it increasingly difficult to communicate. Finally, he was unable to speak. Other group members gradually, tactfully and unobtrusively took over the duties of the founder member on the basis of an unspoken mutual understanding. Their founder member remained their founder member, however, and a figure of respect, whose involvement they still wanted. They kept it by beginning each meeting by handing him a book of poetry, which he would open. They would read the poem on the page, thank him and open their meeting. He had kept an important role.

6. Further Reading

Any of these will help you take things further. Please see Young, Manthorp and Howells (2010), detailed below, for a more extensive bibliography.

Adams, T. and Gardiner, P. (2005). Communication and interaction within dementia care triads: Developing a theory for relationship-centred care. *Dementia*, 4 (2), 185-205.

- This article emphasises the importance of a good communicative relationship between professionals and formal carers, people living with dementia, and their family members.

Alzheimer's Society (2009). Website, available online at <http://www.alzheimers.org.uk/>

- There is an excellent factsheet on communication and dementia – see http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=783&pageNumber=3.
- There are also regular news items: see, for example, http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=313, for a news article which explains why patronising talk inhibits care, and http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=783&pageNumber=3 for an article that explains that not answering a question does not necessarily mean that a person living with dementia does not understand.

Hargie, O. and Dickson D. (2004). *Skilled Interpersonal Communication*. 4th edition. Routledge, Hove.

- A very good general introduction to research into communication.

Killick, J. and Allan K. (2001). *Communication and the Care of People with Dementia*. Open University Press, Buckingham.

- A wonderful book exploring communication and care of interest to anyone touched by dementia.

Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Open University Press, Philadelphia, PA.

- A founding text describing the idea of a 'person-centred' approach.

Savundranayagan, M. Y., Ryan E. B, Anas A. P. and Orange J. B. (2007a). Communication and dementia: Staff perceptions of conversation strategies. *Clinical Gerontologist*, 31 (2), 47-63.

Savundranayagan, M. Y., Ryan E. B and Hummert M. L. (2007b). Communication, health and ageing: Promoting empowerment. In A. Weatherall, B. M. Watson and C. Gallois (Eds.) *Language, Discourse and Social Psychology*. Palgrave. Basingstoke.

- Two articles which show how people are going about conducting research into communication and people living with dementia.

Young, T. J. & Manthorp, C. (2009). Towards a code of practice for effective communication with people with dementing illnesses. *Journal of Language and Social Psychology*, 28 (2), pp.174-189.

- An article where we explain the technical and theoretical background to DEMTEC, and where we highlight the need for more effective communication involving people living with dementia.

Young, T.J., Manthorp, C. & Howells, D. (2010). *Communication and Dementia: New Perspectives, New Approaches*. Barcelona: Editorial Aresta. ISBN: 9788493787097.

Available in a Spanish language edition as "Comunicación y Demencia. Nuevas Perspectivas, Nuevos Enfoques", ISBN: 9788497889117, and in Catalan as "Comunicació i Demència. Noves Perspectives, Nous Enfocaments", ISBN: 9788497889377.

- A detailed look at recent thought and practice which recognises the central role of communication in the lives of people living with dementia.

Young, T.J., Manthorp, C., Howells, D. & Tullo, E. (Forthcoming, 2011). Developing a carer communication intervention to support personhood and quality of life in dementia. *Ageing and Society*, 31.

- A full account of the consultation process and development of a final version of a 'core' toolkit and its future evaluation.