RESPONDING TO PEOPLE WITH DEMENTIA

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Sometimes it is difficult for workers to know how to respond appropriately to people with dementia. By saying things that are apparently meaningless or easily mistaken, people with dementia are vulnerable to losing their adult and human status. Reality orientation is of use in the early stages of dementia. In the later stages, collusion and deception become tempting and well-meaning options. This paper argues that responses should be based on the two principles of non-confrontation and honesty and goes on to describe a working framework off our useful responses that are in accord with these principles.

THE NUMBER of specialist homes for old people with dementia is increasing, as is the proportion of residents with dementia in non-specialist old peoples' homes. There is an urgent need to develop principles on which practice with this client group can be based. A start has been made with the publication of BASWs Guidelines for Social Workers Working with People with Dementia and their Carers (Marshall, 1988), but such guidelines of necessity are pitched at a general level. People with dementia are extremely vulnerable to dehumanisation and infantisation. If workers are to value people with dementia as adult human beings, a way has to be found to maintain their human and adult status. This article focuses on the problem of how workers should respond to the apparently meaningless or easily mistaken verbal and non-verbal communications from residents. Before outlining a working framework, I will briefly discuss decision-making, giving and withholding consent, and non-verbal communication, three important areas for workers in this field to consider.

Dementia involves the progressive loss of some cognitive abilities, particularly in the area of decision-making. This poses workers with considerable ethical problems and leaves people with dementia particularly vulnerable. Two of the most important abilities are the ability to recognise that a decision is required and the ability to make an informed decision. Typical of the everyday ethical problems faced by workers is a resident going out for a walk without adequate clothing when the temperature outside is below freezing. Should workers insist that the resident has adequate clothing on? Workers may be reluctant to do this as they believe that the resident has the right to decide whether or not to put extra clothing on. On the other hand residents have, as does everyone, responsibilities and one responsibility is not to expose themselves unnecessarily to harm. At times we may wish to relinquish our responsibilities in order to pursue some purpose. Workers need to consider whether the person is making a purposeful decision and whether the decision is fully informed. Using the example above: is going out without adequate clothing a positive decision that has been taken in the knowledge of the low temperature outside and the risk of hypothermia? In addition, workers would have to consider whether the person has retained the ability to take a second decision of whether or not to stay outside without adequate clothing. Has the person concerned lost the ability to recognise cold or the ability to act upon that recognition?

The issues around the ability to take informed decisions leave people with dementia vulnerable to the loss of the rights of risk and choice and subjects workers to contradictory pressures between safety and
risk, and between rights and responsibilities.

In many areas of professional practice and everyday life, consent is assumed rather than explicitly required. In the absence of an indication to the contrary, a person is assumed to be consenting. Explicitly given consent is not normally required. There are exceptions to this, for example, consent for administration of an anaesthetic, surgical operations, marriage, legal contracts of various kinds. But by and large we do not lead our lives giving explicit consent either written or verbal. The ability of residents to protect themselves depends as much on being able to communicate that they do not consent, as being able to give consent.

Consenting to a sexual relationship is an area of particular concern to both workers and relatives. A resident may enter into a sexual relationship with another resident who has lost the ability to communicate that they do not consent. Such a situation raises many difficult questions. What would constitute rape in these circumstances? How much weight should be given to the views of relatives who are unhappy about the situation? Should an advocate be identified to take decisions on behalf of the person with dementia? On what basis would decisions be taken? Would decisions be taken on the basis of known pre-dementia beliefs and values or would the person with dementia be regarded as having changed from their pre-dementia self?

These are very difficult questions with no easy answers. Taking a very protective role could be limiting the human potential of the person with dementia. A laissez-faire attitude, of not interfering unless there is an indication that consent is not being given, leaves the person with dementia vulnerable to gross exploitation. A resident's inability to indicate whether they consent or not leaves workers with a dilemma. In the absence of any indication from the resident, on what basis do workers act? Do workers assume that such a person is consenting or do they assume they are not consenting?

Both workers and people with dementia communicate non-verbally, with or without words. Tone of voice, posture, stance, demeanour, eye contact, facial expressions and actions together contribute to the overall communication. Long after a person with dementia has lost the ability to make and understand verbal communications, they may retain the ability to communicate non-verbally and remain sensitive to the non-verbal communication of others.

When workers are trying to interpret the communications of people with dementia, non-verbal aspects will be as important as any words that may be used. Workers need to become sensitive to both verbal and non-verbal clues as to what people with dementia are communicating. They should develop ways of interpreting these clues and respect the dignity, humanity and wholeness of the person with dementia.

People with dementia remain sensitive to, for example, tone of voice. When workers are responding to people with dementia, the words used may not be particularly disrespectful or oppressive but the tone of voice may communicate disrespect. When words have lost their meaning, anger, irritation or contempt will still be communicated through tone of voice. Another important aspect of non-verbal communication is the expression of affection. Some people with dementia are particularly
responsive to expressions of affection. These are usually expressed non-verbally through, for example, touch, physical proximity, eye contact and tone of voice.

In many ways non-verbal communication is more important than communication through words. Despite this, the rest of this paper tends to focus on verbal communications of workers and residents. This is because in a written paper it is easier to discuss specific approaches in terms of the verbal aspect of communication. It must be constantly borne in mind that within each approach, non-verbal communication is equally important. So when, for example, workers distract a resident they do this verbally and non-verbally and the meaning of the workers' communication to the person with dementia will depend on both non-verbal and verbal aspects of workers' communications.

Social work with people with dementia is very exacting and it may appear at times that workers in this field are expected to display superhuman and saintly qualities. Workers should struggle to maintain professional values in these very difficult circumstances and I intend to provide a working framework that will help them to respond constructively to people with dementia. Interactions with people with dementia should be guided by the principles of non-confrontation and honesty. At first sight these two principles may appear to contradict each other. It may appear that if we are to remain honest, the person with dementia should be confronted, re-orientated or brought back to our reality. But this paper presents alternatives to confrontation that remain honest.

Confrontation is a recognised response of drawing attention to contradictory statements (Kadushin, 1983, p. 195). A confrontative response would be when a resident refers to her dead husband as if he is alive and the worker responds by saying: 'Your husband has been dead for two years'. People can be confronted with reality, gently and sensitively, and in the early stages of dementia this may be the most appropriate approach, the person concerned being brought back to our reality without agitation or upset. Skill and sensitivity are needed when confronting people, if it is not to become an oppressive, demeaning and belittling experience.

The principle of non-confrontation means respecting the personal reality of people with dementia and not imposing our definitions of reality upon them. In the reality of people with dementia, what time it is, where they are, and who is around them, may cease to be important. In the later stages of dementia, the principle of non-confrontation tends to be more and more important and confrontation tends to become unhelpful. Confrontation should not be confused with non-intrusive information giving. Workers stating their names and the displaying of information about the current season, always provides useful orientating information if this can be done in an adult way (Rimmer, 1982).

If in the later stages of dementia, it becomes less and less important to impose our reality, how are workers to respond to apparently meaningless or mistaken communications? The principle of honesty means remaining truthful to residents and so rejecting collusion and deception. It is tempting for workers to either collude with or deceive residents. Short-term memory loss means that deception can be easily accomplished and collusion can appear to be the kindest thing to do and less time-consuming. An example of
collusion is when a worker responds to a resident, who refers to the worker as ‘son’, with ‘Come on Dad it’s time to go to bed’. An example of deception is when workers entice wandering residents back home by saying that their favourite dinner is on the table waiting for them, when it is not. Workers using collusion and deception may be well-meaning and not aware of what they are doing. It may not appear to be wrong to ask a wandering resident to come in for a cup of tea but not actually give them one. The resident may have forgotten they were offered a cup of tea, but if they are to be accorded respect they should not be deceived. Collusion and deception demean both the worker and resident. When used, they contribute to the resident's disorientation and betray trust.

This paper presents four types of responses that uphold the principles of non-confrontation and honesty. The four responses of tolerance, reflection, distraction and validation all offer alternatives to confrontation, collusion and deception.

Tolerance

Tolerance is related to the principles of acceptance and non-judgementality but more accurately reflects the likelihood that, faced with the particular pressures of working with people with dementia, workers can become exasperated. There will be limits to tolerance. Yet even if many of the actions of people with dementia are extremely irritating they are generally relatively harmless. For example, continually taking empty milk bottles out and then bringing them back in again or standing in the corridor asking passers-by when the next bus will be along. By arguing that workers should be tolerant of such activities I do not mean to imply that they are without meaning. If workers can be creative and have a full knowledge of the residents’ personal history they can make such activities meaningful and so accord them respect. By the use of constructed meanings, workers can move from a position of tolerance to one of appreciation.

Other actions involve the imposition of indignity on, or danger to, the person with dementia or others (including workers). The trouble with notions like indignity and danger is that they are relative and not absolute. Certain amounts of danger and indignity may have to be accepted. The question is where to draw the line? For example, should a worker do something about a resident stripping off their clothes in the lounge? How far should the sensibilities of other residents be protected? Other residents and staff should not be subjected to physical violence but what about verbal abuse? How far should the pre-dementia views of residents be used as a guide as to what is acceptable and what is not? These questions of what should be tolerated and what should not are complex ones raising many issues.

Working with people with dementia in residential settings requires great tolerance but there will always be limits. What these limits should be is a problem. The rights of others (both residents and staff, the pre-dementia opinions of the resident and the dignity involved in being a human being are among the issues to be considered, but there are no easy answers.

Reflection

In much work with old people in general and with people with dementia in particular, the principles and techniques of counselling appear to
be forgotten. The reflection of feeling and reflection of content are two ideas drawn from counselling. Rather than commenting or asking another question, the worker simply reflects back to the client in a tentative manner, what they have just said. The intonation is often enquiring but there is no need for an answer. The worker can either focus on the feeling level or the content level. The client has the opportunity to continue without interruption and the worker is provided with a check as to whether they are listening and understanding correctly. Reflection of content is usually a relatively straightforward matter. Reflection of feeling calls for an accurate reading of how the client is feeling. This is obviously more difficult and hazardous and places much importance on workers checking out whether they have understood or not. It requires sensitivity, empathy and a degree of interpretation.

Example:

Client: I want to go home. I don't like it here. I want to go home to my mother.

Worker: You want to go home (reflection of content).

You are missing your home (reflection of feeling).

A person’s need to substitute the past for the present can be left unquestioned by being selective about which aspect of content to reflect or by the reflection back of the feelings involved. In work with people with dementia, reflection of feeling will be of most use as it acknowledges unexpressed emotional needs rather than the content of what is said.

Distraction

There will be times when workers are unable just to let residents get on with what they are doing and reflection will be of little use. At these times it may be possible to distract the residents. There is the danger of being disrespectful, as skill and sophistication are needed if residents are going to be distracted successfully while they retain their value as people. Distraction calls for creativity from the worker, as well as knowledge of the likes and dislikes of the person concerned. What distracts a person may be very specific to that particular person. It is tempting at times to distract with something that is untrue, but high value should be given to honesty: creativity and personal knowledge should be relied upon to produce basically honest distractions. A person wandering off should only be distracted with, 'Your dinner is ready', if her or his dinner is ready. A resident about to expose themselves to visitors can be discreetly distracted by a worker without anybody noticing anything untoward. The question of when to distract is a difficult one to answer. There is always the danger of just imposing our own values and protecting our sensibilities. The rights and freedom of residents are at stake.

Care needs to be taken that workers do not only respond to anti-social behaviour. Acting in certain anti-social ways should not be the only way people with dementia receive attention. By only responding to problems, workers can inadvertently contribute to the very actions they regard as problems. Workers should take care to respond to people with dementia when they are not causing them problems.
Validation

Validation is an approach which regards the communications of people with dementia as meaningful. It makes their apparently meaningless or mistaken communications valid. This approach was developed by Naomi Feil (1983). The meaning of some of the communications of people with dementia are not immediately clear to us. Meanings can be constructed using ideas such as: past time/present time, dictionary words/non-dictionary words, metaphor and re-assurance.

Present time/past time

If we could become less fixed in our notions of time and space, the difference between present time and past time could become more fluid. The person with dementia might need to move backwards and forwards between the present and the past. Their present reality may have become so unbearable that they need to retreat back into the past to a time when they felt useful and valued. They may need to go back to resolve what has been left unfinished. Rather than explaining the actions and utterances of people with dementia in terms of mechanistic brain damage, more meaningful and poetical explanations can be developed. This does not mean that workers collude with residents, for example, pretending they are back in a time when they were children. But workers can respond in a way that validates the person's need to go back in time. For example, tentative enquiring but rhetorical questions can be used: ‘You had a happy childhood?’ or ‘You had an unhappy childhood?’.

Non-dictionary words

At times, people with dementia use words that are not in our dictionaries. Rather than just writing such words off as meaningless we can perceive the resident as communicating with non-dictionary words. We can search for the meaning of such words or accept that we don't understand. Again, knowledge of the personal history of the person helps to unravel the possible meanings of these words, although such words may have different meanings in different contexts. Naomi Feil offers the following advice:

With the disoriented elderly person who uses personally constructed, non-dictionary words, repeat the words, emphasising the key words in their sentences, attempt to draw out the patient's emotional need. There are three needs in particular that these patients seem most often to express: the need to belong; the need to be useful; the need to express strong feelings of anger, sadness, or love.

Example:

Mrs K: This Fendalle company doesn't distangle the messy congruents.

Physician: Mrs K, does the Fendalle company bother you? Are the congruents too messy?

Mrs K: Meaningful friends from the company will untangle the mess in the noodles of the brain.

Physician: Do you mean that you miss your company? IS that what 'Fendalle' means?
Mrs K: Yes. Memorable friends from the past.

Physician: We can take a trip to the past using the imagination can't we?

Mrs K: Oh yes. And the company will pay the fare. They always do.

In this scenario, the physician plays along with the patient's ambiguous words and phrases. He [or she] does not need to understand each word. He [or she] understands that the disoriented elderly patient may no longer be able to use dictionary words, and that the words used are often combinations of similar word sounds which nonetheless may have real meaning (Feil, 1984).

Metaphor

The communications of people with dementia can also be thought of as indirect communications in need of interpretation. They could have strong metaphoric or symbolic content. What they say may be literally untrue but metaphorically correct. Detailed knowledge of the person's history, particularly occupational history, can help to make the connections between the past and the present and aid the deciphering of the indirect messages. For example, the resident may need to grieve for the series of losses that being old and in residential care can entail. The grief may not be expressed directly but through metaphor, for example, through the continual searching for a lost item.

Reassurance

Reassurance is a particular type of validation. The actions of people with dementia that prove difficult for carers can be understood in terms of the residents' need for reassurance. Dementia must be a frightening experience particularly during its early stages when there will be a certain amount of awareness of the loss of mental faculties. Much distressed behaviour can be interpreted as the seeking of reassurance that, for example, the person with dementia will not be left alone. The person concerned may be unable to communicate his/her feelings directly and the worker needs to be sensitive to this need for reassurance. Reassurance is responding not so much to the content of what is spoken but to the feelings expressed. Apparently meaningless or out of context questions, remarks or behaviour can be interpreted as expressions of anxieties or fears and can be responded to with reassurance that, for example, they will not be left alone.

Those who believe in the one objective reality will have trouble with these ideas which view reality as individually and collectively constructed, negotiated and multi-faceted. Setting aside a relative view of reality for a moment, both the nature of the human brain and the pragmatics of practice lend support to validation as an approach. The human brain is infinitely complex and beyond our present understanding. In dementia, parts of the brain fail, but until actual death others remain active. Given the complexity of the human brain, it is not beyond belief that this activity remains meaningful at some level. Even if workers do not accept the validity of such meanings at any level, it can be argued that acting as if they are meaningful enhances practice by bringing meaning to otherwise meaningless interactions.
Wandering and aggression are examples of the difficult actions workers face when working with people with dementia. Wandering can be regarded as aimless and mindless, or be made valid as a purposeful searching for something lost or an expression of our basic inclination to travel, wander and explore. It is not hard to see how the ideas of tolerance, reflection, validation, and reassurance, coupled with preparatory work with the community and the acceptance of a certain degree of risk, can be used in the 'management' of wandering without infringing the basic human right of freedom of movement. Depending on the degree of risk and other factors, a resident can be allowed to wander, accompanied or unaccompanied, or distracted back.

Like other behaviour, aggression can be responded to on the basis of its meaning. Aggression is sometimes seen as simply the loss of control due to brain failure but is often the acting out of frustration, anger or anguish. Aggression can be prevented by the avoidance of any type of confrontation. Distraction and reassurance can be used to circumvent aggression that does occur. Giving behaviour meaning accords the individual respect thus bringing human dignity to these difficult transactions.

Workers should take a proactive rather than a passive approach towards relatives. The values and philosophy of workers should be clearly and simply explained to relatives and their assistance sought in carrying them out. Most relatives of people in residential care feel guilty to some extent and at some level. This guilt is eased by the reassurance that their relative is being provided with things that they could not provide themselves - safety, protection and supervision. Practice based on the principles of honesty and non-confrontation using the responses of tolerance, reflection, distraction and validation may at times leave relatives confused and bewildered. They may feel their relative is not being sufficiently protected or they are being allowed to do the things that prompted their admission into residential care in the first place. Relatives need understanding, support and counselling but this should not detract from the fact that it is the person with dementia that is the client. People with dementia should be respected and treated as autonomous human beings with their own wishes, aspirations and needs.

Residential workers need to work together as a team. This requires the development of a common philosophy of care. The working framework provided can form the starting point for the development of such a philosophy. Alongside team development, workers will need training and education in the principles and practice of the working framework. The workers' initial response may be that the approach is all very well and good, but there is only time to respond adequately to the physical needs of residents. Such a response is a specific example of the more general problem of shifting the emphasis from physical care to social care.

Workers may also find the approach a contrast to their previous practice which may have regarded communication with a person with dementia as a one-way process. They may have been blind to the communications coming forth from the person with dementia. Their practice may have been based on care, pity and affection and the implication of it being based on respect and meaning are considerable both for workers and residents.

Working with people with dementia can be trying and difficult as well
as rewarding. The principles of non-confrontation and honesty offer some guidance to workers as to how they should respond to apparently meaningless or mistaken communications of residents with dementia. Tolerance, reflection, distraction and validation enable workers to put these principles into practice, a practice based on skill, creativity and knowledge of individual residents' past and present selves. These responses form a working framework within which to respond to people with dementia. They are not so much separate responses, but different ways of respecting the actions of people with dementia as meaningful. If workers start to see their work as meaningful, skilful and purposeful, there will be an increase in the quality of worker/resident transactions.

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References


