

# **Dementia and social death**

Paul Spicker

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**Abstract.** *Social death occurs when a person's social relationships and identity are dissolved. Dementia involves progressive loss of faculties and withdrawal from social activity and relationships. It is commonly viewed, questionably, as a condition which wholly disables its sufferers, who are treated as if they are incapable of recognising their problems, feeling, responding or relating to others in a meaningful way. People with dementia undergo a period of progressive removal from society, in which they become 'non-persons'. This implies the erosion of the 'self' in social terms.*

The idea of 'social death' was introduced to the literature on elderly people by Miller and Gwynne, in the context of a critical discussion of residential care. They write:

To lack any actual or potential role that confers a positive social status in the wider society is tantamount to being socially dead. To be admitted to one of these institutions is to enter a kind of limbo in which one has been written off as a member of society but is not yet physically dead. In these terms the task society assigns - behaviourally though never verbally - to these institutions is to cater for the socially dead during the interval between social death and physical death. (Miller, Gwynne, 1972, p.80)

The terms in which the idea is stated suggest that the idea of social death is mainly an analogy: lacking roles is 'tantamount' to death. But the concept is potentially stronger than this. In sociology the nature of a 'person' is widely understood in terms of by reference to the person's social relationships (Dahrendorf, 1973). The concept has been criticised for its failure to take into account other aspects of human knowledge and experience (Wrong, 1967), but it offers nevertheless an interesting insight into the nature of the 'individual'; we are social animals in a sense which is much deeper than that of belonging to a group of people. It is from our social relationships that our actions and our existence acquire meaning, both to others and to ourselves.

If people can only be understood by reference to others about them, this leaves the curious possibility that a person who is effectively cut off from society might cease to exist in social terms. 'Social death' does not imply that a person vanishes altogether, because in social terms people who are physically dead do not really cease to exist, either. They have been part of a pattern of social relationships, and aspects of those relationships continue to apply after death - for example, in laws relating to wills and succession. Social death might be seen as a form of analogy with physical death (e.g. Finklestein, 1991), but the possibility of 'social death' is more than an analogy; a person whose social relationships cease, and whose property is dissolved and distributed, may continue to exist in body but not in other respects.

## The experience of dementia

Dementia is not one disease, but a range of conditions associated with a pattern of experience. Roth defines dementia as

a global deterioration of the individual's intellectual, emotional and conative faculties in a state of unimpaired consciousness. (Roth, 1981, p.24)

The deterioration of intellectual faculties implies that sufferers become progressively less able to retain new information, and so to absorb it. They become gradually cut off from their environment. The term 'conation' refers to a person's will and directed activity, and the loss of conation means that the person with dementia becomes unable to behave autonomously. The deterioration of emotional faculties becomes evident in behavioural disturbance, emotional lability, passivity and inappropriate reactions.

Dementia is a distressing condition, and there has been a great deal of research describing its effects. The main problems identified in the literature concern the burden on carers; the capacity of carers; and the behaviour of the sufferer. (Argyle, Jestice, Brook, 1985) The primary determinant of stress in the carers is the impact of dementia on the sufferer's activities in daily living - i.e. functional disability - rather than the level of cognitive incapacity (Poulshock, Deimling, 1984; Deimling, Bass, 1986). Gilhooly et al comment that  
Although memory loss, disorientation, disinhibition, emotional and personality changes are common to all dementias, it is of course not these symptoms but the consequences of these changes in individuals ... which are problematic. So, for example, memory loss per se would not be problematic if it did not lead to paranoid reactions when things cannot be found, or to inability to recognise one's own home and relatives. (Gilhooly et al., 1994, p.31)

By 'problematic', they mean problematic for carers.

The main limitations which create burdens for carers are physical dependency, and concern self-care, incontinence, and illness. O'Connor et al record several problems carers had with physical dependency, including dressing, washing, meals, getting people in and out of a chair or in out of bed, or urinary and faecal incontinence. Some of the problems reported are clearly problems of supervision related to cognitive impairment; they include concerns about stairs, feeling that people can't be left, a feeling that they couldn't be allowed outside, or fear of their falling. (O'Connor et al, 1990) Many of these comments apply equally to people without dementia, but it seems clear that there is greater stress for the carers of people with dementia (Eagles et al, 1987); this seems to relate less to physical dependency than to issues of behaviour.

The problems of behaviour reported by carers are varied, and often expressed in different terms, but certain themes recur in different studies. Greene et al distinguish three: disruptive behaviour, confusion and apathy. (Greene et al, 1982) There are at least two more, which are related to the others: impaired social interaction, and problems in the relationship between sufferers and carers.

*Disruptive behaviour.* Greene et al include in this category problems when the sufferer changes mood changes for no apparent reason; becomes irritable and easily upset; goes on and on about certain things; accuses people of things; becomes angry and threatening; appears unhappy and depressed; or talks all the time. For O'Connor et al, disturbed behaviour includes demanding attention, repeating questions, bad language, vulgar habits, noise, personality clashes, temper outbursts, aggressiveness, rudeness to visitors, wandering at night and disrupting the carer's life. Baumgarten's 'Behavioural Disturbance Scale' - more a checklist of misbehaviour than a scale - refers to many of the same problems, including also hoarding things, pacing up and down, dressing inappropriately, screaming for no reason, physical attacks, throwing food, and destroying property or clothing. (Baumgarten, Becker, Gauthier, 1990) Collins refers to carer's concerns that sufferers would follow people about the house; worrying easily; and seeking attention. (Collins, 1983) Rabins et al add catastrophic reactions, demanding things, night walking, and hiding things. (Rabins, Mace, Lucas, 1982) While understanding why these actions are considered disturbing, it is worth saying that many of them are also disturbing to the sufferer (losing things, getting lost, becoming incontinent); indicative of disturbance (crying or laughing, making accusations, cursing); and even possibly indicative of resentment against the carer.

*Confusion.* The cognitive impairment associated with dementia can be a source of stress in itself. O'Connor et al refer to problems when sufferers are forgetful, cannot read, and cannot follow tv or radio. Greene et al's respondents note that sufferers do not respond sensibly when spoken to; do not understand what is said to them; do not watch and follow television; fail to recognise familiar people; get mixed up about where they are; get mixed up about the day or year; has to be prevented from wandering outside; hoards useless things; talks nonsense; appear restless and agitated; get lost in the house; wander at night; wander and get lost; endanger his or her self; and seem lost in a world of their own. Collins refers to repetition of speech, loss of memory, fixed or recurring ideas, disorientation about time or place, habitual use of stock phrases, losing possessions, and failing to recognise people. Rabins et al add hallucinations and delusions.

*Apathy* Apathetic behaviour is associated with the loss of conation. It may be evident in the loss of interested activity and social contact - Collins notes carers' concerns that sufferers do not initiate conversations, and Greene and O'Connor et al that they have no interest in news about friends, relatives or the outside world. The issue, Greene argues, extends beyond this, including neglect of appearance and hygiene.

*Impaired interaction* It is difficult in practice to separate impaired social interaction from issues of communication. O'Connor et al note the comments that sufferers cannot converse sensibly and cannot talk with family; Greene, that they cannot start and maintain a sensible conversation. Collins reports other comments, among them that sufferers are 'difficult to convince of reality' (a comment made by most respondents).

*Relationship problems* This, in turn, relates to another issue: strained social interactions associated with disturbed behaviour. There is a long list. Collins' respondents complain of stubbornness, lack of thought for others, tantrums, complaints, ingratitude, false accusations and aggression. But the list goes beyond this, including complaints that the sufferer stays awake at night, allows kettles and pans to burn out, leaves the front or back door open, doesn't wash hands after using the toilet, and will lie about having a wash. Rabins notes comments about smoking and inappropriate sexual behaviour. Baumgarten notes problems of exposing oneself and refusing to be helped with personal care. It seems clear that many of these are fairly directly related to the problems of dementia, but equally there are contexts in which many of them might not. Many old people stay awake at night, because they take less sleep. Standards of personal hygiene have changed over time, but many people would resent having them questioned. Smoking has become less prevalent in younger age groups. There may also be an issue of relationship with the carer; stubbornness, lack of consideration and false accusations seem to tie in with personality clashes and some other aspects of rude and aggressive behaviour.

#### *The problems for carers: an overview*

The literature on carers is large, and it has been subject to some fairly stringent criticism. Barer and Johnson argue that the definitions of 'care' and caregivers' are confused, and that the samples are self selected. They also make the central point that the needs of elderly people themselves are not considered. (Barer, Johnson, 1990) In the context of a discussion of carers' needs, this is an important general reminder; the interests of carers and sufferers may conflict, and both need to be taken into account. In the context of writing about dementia, however, the issue goes much further. The problem is not just that the needs of sufferers are overlooked; they do not seem to exist at all. Issues like incontinence or the inability to dress oneself are commonly presented, in the literature considered here, as problems *for the carer*, not for the person who is being looked after.

The problems of carers are clearly important; there are too many cases where these problems have been overlooked or ignored (Bayley, 1973; Parker, 1990). Carers feel tied. The limitations to the carer's social life included the effects on relationships, including a

decreased social life, and conflicting family demands; the physical demands of caring, including problems in washing clothes and shopping; and material demands, including overcrowding and lack of financial support. Argyle et al. list among the limitations of carers their embarrassment; anxiety depression; physical weakness; lack of confidence; arthritis; and shortness of breath. (Argyle, Jextice, Brook 1985) These are important problems, which should not be overlooked. In the case of dementia, the problems of caregivers have been examined virtually to the exclusion of the problems of sufferers. This may, realistically, reflect the situation where caregivers, not sufferers, make decisions about the demand for services (Colerick and George, 1986; Gilhooly, 1986); but it seems, beyond this, that the problems which sufferers experience are treated in the first instance as problems of the carers. For example, Gilleard et al's study of problems in caring for the elderly includes five main categories:

- dependency - dressing, feeding, communication, washing, not safe outside, not left alone;
- disturbance - accusations, temper outbursts, bad language, aggression
- disability - faecal incontinence, urinary incontinence, help into bed, not manage stairs;
- demand - demands attention, disrupts social life, creates clashes, noisy, always questions
- wandering: wanders at night, wanders during day. (Gilleard, Boyd, Watt, 1982).

But dependency and disability are primarily problems for sufferers, not for carers. Deimling et al write:

"Much of the strain that is associated with caregiving can be understood by examining the impairment of the older relative. Most problematic are the physical health problems that cause urinary or bowel incontinence, or those that require heavy lifting, such as transferring and toileting. Other research has shown that the elder's mental incapacity also is an important predictor of care related stress." (Demiling et al, 1989, p.68)

What many of the articles cited have in common is that they are all about the problems of carers; but hardly any of the issues considered might not be thought to indicate that the sufferer has problems. I do not wish to argue that the focus on carers is in any sense illegitimate; but what seems to have happened in the process is that the person with dementia has become a cypher. That runs the risk of reinforcing a significant and destructive stereotype - that a person with dementia is in some sense dead - that 'the person you knew has gone'(Cooper, 1985).

### **The view from the sufferer**

By contrast with the position of carers, we know very little about what it is like to experience dementia - if only because people with dementia are hardly ever asked. There are some creditable exceptions in recent work. (see Marshall, 1997) If they are able to answer, the assumption is likely to be made that they are not that demented; if they are not, it is only what one expects from people with dementia. There is a dangerous assumption concealed in this: that people with dementia have become a kind of human vegetable, incapable of reaction, feeling or normal emotion (a view reinforced because the disturbance of such responses is part of the diagnosis of the condition). But there are important reasons to question this view. Kitwood and Bredin make a strong case that people with dementia are responsive to their social environment; even responses which are socially inappropriate (trying to clean up after incontinence with an item of clothing) still show a degree of social awareness, while in other cases there may be 'reementia' or a positive regain of abilities through social interaction. (Kitwood, Bredin, 1992)

The faith that people with dementia must be able to communicate has generally been rewarded. Killick comments:

"To see the struggle for expression on people's faces, to hear the sounds tumbling over themselves in an effort to become words, phrases, sentences - this is painful. But when communication has been achieved, when the individual has leaped across the barrier to attain an utterance which embodies an insight - this is inspiring, often for both parties." (Killick, 1997)

My colleague Brenda Gillies has undertaken some interviews with sufferers; they describe the effects of their illness as 'horrible', 'rotten' and so forth.

*Does it perplex you that you can't remember?*  
Of course it does. How would you like it? (Gillies, 1995)

This kind of work depends centrally on the supposition that people with dementia do have feelings, and can express themselves, even though their communication is impaired. By way of illustration, it may be helpful to concentrate on an exchange between a sufferer from dementia and her carer. This was originally used in a documentary entitled *Where's the Key?* and subsequently used by the Open University.

*Daughter:* Look, you are tired, aren't you?  
*Mother:* Yes, I am.  
*Daughter:* Why don't you go to bed, love?  
*Mother:* Will we have yoghurts ...?  
*Daughter:* No, you got yoghurts tonight, didn't you?  
*Mother:* Yes, and er ... (pause)  
*Daughter:* We've got plenty of custard tarts, and we're going shopping on Wednesday. All right?  
*Mother:* Yes.  
*Daughter:* Well then, why don't you go to bed?  
*Mother:* I don't know. I don't know. (Sobs)  
*Daughter:* What don't you know, love?  
*Mother:* I don't know.  
*Daughter:* What does it feel like? Tell me.  
*Mother:* (Sobs)

There is certainly evidence of confusion and memory loss. The mother finds it difficult to find words and to complete sentences. In the commentary, the mother is described as 'pathetically confused', and unable to express her feelings. But this is not true all the time:

*Daughter:* What is the matter, love? Can't you tell me?  
*Mother:* Er -  
*Daughter:* Are you afraid?  
*Mother:* Yes, I am afraid.  
*Daughter:* What are you afraid of, love? Tell me, and I'll help you.  
(Pause)  
*Mother:* (sighs) Oh god.  
*Daughter:* Would you like to go and live in a hospital, mummy?  
*Mother:* No, no, I don't want to go and live in a hospital.

In this exchange, the mother answers two questions relevantly and without hesitation. This could be because the answers were learned long before; it might also be that the daughter has provided the words with which the sentiment can be expressed. But the exchange does bear another interpretation. Assume, for the moment, that the mother is aware of her memory loss; that she is aware of her increasing dependence on her

daughter; and that she is able to recognise her daughter's sometimes frustrated and sometimes patronising tone. It happens fairly consistently, throughout the recorded interchanges, that when the daughter says "I want to help you" the mother bursts into tears. When the daughter asks her, "what's the matter?", the answer might well be: "our relationship". But the mother can't say it, partly because she loves her daughter and knows it can only be hurtful, and partly because she recognises her dependency.

Of course the interpretation is unprovable. The analysis supposes, of necessity, that people who have dementia have some degree of insight, and the point is often disputed. It is impossible to prove that a person with dementia has a particular view of the world, a particular kind of insight, or an emotional reaction, but by the same token it is impossible to prove that anyone ever feels anything. In so far as the person is able to express such comments verbally, this would be taken as evidence that dementia has not really progressed to the fullest extent; and whether they do so verbally or non-verbally, reactions are always open to interpretation. The best that one can do - as with much else in the field of human relations - is to seek to interpret the kinds of things people say and do; and here, the evidence is not unequivocal. Given the usual slow, progressive nature of the disease, it is difficult to see how people cannot be aware that their memory is failing. That has implications both for understanding people's reactions when they do have dementia, and for the management of dementia in practice.

### **The death of the self**

Sociologists have often understood the nature of the self in terms of a process, formed through the interaction of the person and the society of which the person is a part (Cooley, 1902; Mead, 1934). Dementia is a condition in which the self is gradually eroded, both in a psychological and a social sense. In psychological terms, the loss of intellectual faculties, the loss of will and the loss of emotional control undermine the person's perception of the self, the self as 'I'. In social terms, people with dementia also witness the erosion of the self through the eyes of significant others - in particular, the people who care for them.

Degenerative diseases are often accompanied by a range of behavioural and emotional changes. The difficulty in establishing the etiology of such changes is that they are often similar to those of people with 'organic personality syndrome', described in DSM-III, the psychiatrist's diagnostic manual, as involving emotional lability, aggressiveness, an alteration in social values (for example inappropriate sexual behaviour), apathy and mistrust. The same patterns of behaviour are sometimes present in people with dementia. Although they can be seen as organic in origin, it is no less plausible to see them in terms of a social reaction to disease. The common reactions to bereavement identified by Murray Parkes are a process of identification - often initially denying the circumstances; alarm, including anxiety and restlessness; 'searching' for the lost person; anger and guilt; feelings of self loss or mutilation; and 'identification phenomena', including attempts to behave as if the loss had not happened. (Murray Parkes, 1972) The development of a condition like dementia, like physical ageing, implies loss of faculty, adjustment to new limitations, and an anticipation of death. If anxiety, anger and attempts to recapture the past are part of the psychological reaction to physical conditions - Murray Parkes relates his model to the amputation of a limb - it is hardly surprising that they might also affect the pattern of behaviour of someone who realise that his or her cognitive faculties or memory are failing. Some disorders of behaviour associated with dementia become worse as the dementia becomes more severe; they include incontinence, wandering, sexual disinhibition, hyperorality and withdrawal. Others do not, notably aggressiveness and temper tantrums (Burns, Jacoby, Levy, 1990) - which suggests that they cannot be understood solely in terms of the disease; by the same token, the deterioration of other behaviours (e.g. self-neglect) may be related to the increasing seriousness of the impairment.

In the course of dementia, the self slowly dies. People who die physically may not cease to be persons, in the social sense, but they do cease to be aware of the consequences of their personhood on others. People with dementia, by contrast, may well be aware what is happening; but that does not mean that they have the power adequately to communicate that awareness or to govern their interactions with other people. This experience may be shared with others whose ability to communicate or direct their actions, like victims of stroke, but there are important differences. Stroke is sudden and the prognosis generally indicates the possibility of improvement, so the stroke victim enters a sick role in which people make allowances and the stroke victim seeks to improve. The person with dementia is suffering from a degenerative disease, and witnessing the effects of their dying on those around them.

This is not fully equivalent to social death. Dementia leads to a different pattern of experience. The person with dementia has not ceased to exist; there are still important relationships with others. People with dementia undergo a period of progressive removal from society, in which they become 'non-persons'. They enter a kind of limbo, in which they have visible effects on the lives of people around them, and are capable of reaction, but are not accorded the status of persons.

### **Issues of principle**

The picture of dementia sufferers painted in the literature is an alarming one. Sufferers are treated like a body without a mind. This is a husband talking about his wife's dementia:

"Finished, done, dead, dead - they're dead as far as you're concerned, they're dead because they're not the same person they were." (Gilhooly et al, 1994, p.36)

In these circumstances, people are treated as if they are dead - past wishes and relationships are respected, but their present conduct is invalidated.

Even if it could be established that people with dementia do not have insight into their condition, it would not follow that they should be treated as forfeiting rights and dignity. Dementia in old age is not for the most part a disease which changes someone's condition overnight. Two aspects of Roth's definition are crucial. One is the reference to unimpaired consciousness; a person with dementia is not wholly unresponsive. A person with dementia will usually still have some learned skills - notably language - and a set of learned responses, which means that communication is possible. Second, and perhaps most important, is that dementia implies a deterioration of faculties. The model which suggests itself is that of a degenerative disease; dementia is progressive, developing from an initial state in which communication, cognition, emotion and conation are intact.

It is difficult in practice to distinguish behaviours which are meaningful from those which are not. The general moral presumption applied in other fields of human behaviour is that behaviours should be treated as worthy of respect unless there are good reasons to the contrary. There is nowhere where a line can sensibly be drawn to distinguish the 'aware' and the 'insensible', or the 'rational' and the 'irrational'. Even if people with dementia could be taken to be insensible to their circumstances, and it was justifiable to treat people with dementia as without human dignity, at what point can it be said to happen? How can we know that people are not aware? Can the same kinds of treatment be justified for those who do retain some awareness? (Barbara Wootton, after her admission to long-stay psychogeriatric care with dementia, is recorded as commenting: 'I've been making a list of the differences between hospitals and prisons. It's not very long.')

Ultimately, the issue is a moral problem. The argument for treating people with dementia with respect depends centrally on the belief that everyone has to be treated with a degree



of basic respect (Downie, Telfer, 1980; Spicker, 1990). In the case of care for elderly people, we are only beginning to be aware of some of the same kinds of abuses and problems which affect groups who are stigmatised or considered 'non-persons'. Rights and respect are fundamental to the protection of people from abuse.

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