

# Shame and avoidance: issues of remembering and forgetting with people with dementia

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'Shame is like an atomic particle; we often know where it is only by the trace it leaves, by the effects it causes.'

Michael Lewis, 1992

Human beings are social animals: we live and interact with others humans within social structures that are regulated so that behaviour conforms to certain norms or rules. When individuals are perceived to have transgressed the acceptable norms either through their behaviour or individual difference, then those bonds that otherwise unite individuals within a group are severed or diminished. The emotion of shame is experienced when an individual judges that a quality of behaviour that he or she possesses or displays will be taken by others as having broken or exceeded those socially acceptable boundaries or expectations.

The potential for shame is a recurring feature of many aspects of a medical encounter between doctor and patient. When the consultation encompasses behaviours or experiences that would fall into the category of a mental illness then this potential is increased. As Goffman (1968, 19) noted when drawing attention to shame as one of the significant features of stigma, shame arises 'from the individual's perception of one of his own attributes as being a defiling thing to possess'.

## shame

When an individual fears their shameful attributes may be exposed this generates feelings of heightened self-consciousness, insecurity and social anxiety and the expectation of engagement in hostile, critical and unsupportive relationships, possibly leading to emotional abandonment. The exposure is not only to others, but also to one's own eyes. The self, or an aspect of the self is experienced as bad, defective or wanting. Cognitions around self-dislike, self-condemnation and self-denigration, in which the individual has not lived up to personal

expectations or standards, are prominent. Shame is associated with helplessness and loss of control and can be referenced by the individual through remarks about their sense of themselves as being 'stupid' or 'foolish', a 'burden' or an embarrassment to others. Shame has a harsh and intransigent character – it is an all or nothing experience. It is irrational and absolute: we are utterly unlovable and unworthy of care or help (Birchmore, 1997).

Shame is associated with three behavioural strategies: first the individual may attempt to avoid or escape from situations in which there is a potential for exposure of those shameful attributes; secondly, where these perceived flaws have been exposed, the individual may attempt to conceal, cover up or to limit their personal responsibility for these attributes; and finally he or she may deny the existence of these flaws. Shame is thus an experience of alienation – of being separated from others both because it feels incommunicable, and also because of the nature of the relationship with others that comes from shame: of being inferior, with no possibility of improvement, redemption or forgiveness.

Because of this hidden nature of shame, it can be difficult for the therapist or others to work with these feelings, and where shame is present in a strong or intractable form, then the person's fear of exposure may jeopardise his or her capacity to work within group or individual psychotherapy. The shame-filled person's predicament may be intuitively perceived by others who may accede to the individual's implicit demands not to have the shameful aspect of their self exposed.

## shame and the diagnosis of dementia

The neurological impairments, that are defined as Alzheimer's disease or vascular dementia for example, cause many behaviours or behavioural deficits that would, in

other circumstances, be construed as breaching socially agreed norms. People with dementia may not be able to find the words to speak coherently, they may lack the competence to manage their own affairs, they may sometimes even lose control of their bladders. However, much of these behaviours are attributed either directly to the neurological impairment or to a deficit in their care environment. The individual's experience remains that of potential shame – it is their incoherence, their incompetence or their incontinence. The experience of a person with dementia, then, may provide many opportunities for shame-filled episodes.

### i) Avoidance

The social stigma of receiving a diagnosis of dementia has been identified as a key issue in people's experience of the early stages of dementia. When disclosures occur within a malignant social context (Kitwood, 1997) it is more likely that an individual will attempt to avoid being positioned within a shameful identity, and to conceal or to cover up behaviours that confirm the possible validity of that position. In relationship to the diagnosis of dementia this reticence may involve avoidance of memory tests and other social situations or events in which potentially shaming judgements about competence may be made. The exposure of a shaming aspect of self can be experienced as frightening, as illustrated by Keady and Bender's (1998) report of a 67-year-old man with very mild dementia reflecting upon his experience of a memory clinic: 'They kept putting me in a room and asking me to do all these things ... counting and things. I never knew why I had to do it and I didn't want to go back. I got frightened and worried because I knew I couldn't do what they wanted.'

### ii) Concealment

One pervasive feature of the diagnostic process is the variety of

accounts that individuals who have been the subject of a memory assessment generate in an attempt to position themselves as having less personal responsibility for a poor test result. Saunders (1998), for instance, argued that memory clinic patients produced up to five separate accounts in an attempt to create an identity for themselves as competent and credible people. She concluded that 'dementia patients manage and protect their own self-image just like any other person' (p85). These attempts to manage one's own identity – to position oneself within roles that reflect competence rather than incompetence, and to claim attributes that are consistent with previously established story lines may be seen by others as attempts to 'cover up' for a shameful attribute or role (Keady *et al.*, 1995).

### iii) Denial

Attempts by individuals to hide or obscure a potentially shaming aspect of themselves are only possible if that person is aware of the social realities of their compromised identity. However, within the context of the diagnostic process of dementia, assertions of competence rather than admissions of incompetence will often be mistaken by a doctor or psychologist for a loss of insight into a neurological event. Thus all too often the attempts of people with dementia of the Alzheimer's type to avoid potentially shaming interactions or to assert non-shaming social identities are attributed to lack of insight, which in turn is represented as a characteristic of the disease process itself, rather than to the reluctance of the individual to enter into

conversation about what they may experience as shameful. Describing an individual as 'in denial' may well be an example of the fundamental attribution error (Sabat, 2002) in which a behaviour is represented as a supposed property of the individual, rather than being understood as an element of the social situation in which they are engaged.

### shame and restricted opportunities for self-exploration

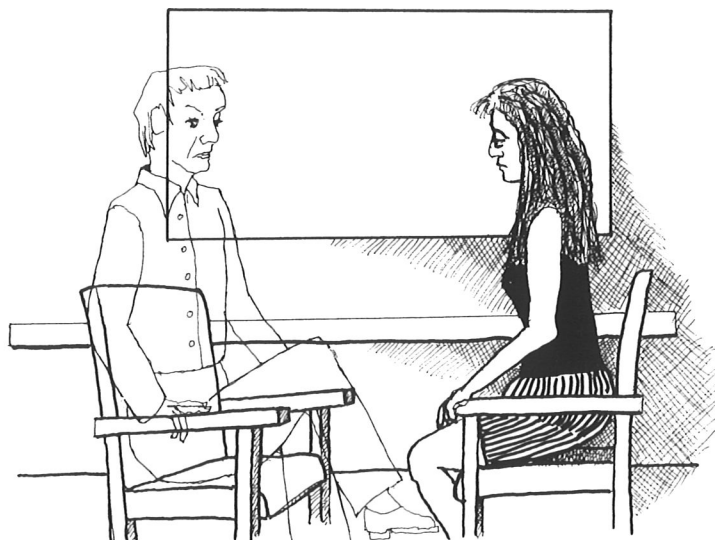
One of the most significant social aspects of shame is the way in which those people around the person at risk of experiencing shame can collude to avoid exposure or discussion of the discreditable aspects of their self. Not only may a person with dementia feel shame at the exposure of their inabilities, but sometimes those people most intimately associated with him or her may be anxious to avoid the distress and hurt that such an exposure may invoke. The fear of exposure of the person's dependency, their inability to remember events and so forth, may engender a similar pattern of concealment, or an unspoken collusion in avoiding the social exposure of the true nature of the difficulties that they face. It is as if the shame-filled person's predicament is intuitively perceived by others who accede to the individual's implicit demands not to have the shameful aspect of their self exposed. At other times it may be that caregivers' own shame at these changes in their partner or their parents may result in angry confrontations, or a refusal to discuss or to accept their existence openly.

Gilbert (1998) refers to these patterns of interaction as shame-inducing spirals in which the risk of experiencing shame acts to inhibit a range of otherwise normative behaviours aimed at reducing interpersonal tension. Shame in this way becomes a taboo – it becomes the non-problem, that which exists but which cannot be spoken about, and which underscores acts of concealment, cover up and collusion.

### group psychotherapy

Experiential group therapy for people with dementia has been characterised as allowing the development of a safe and secure base from which to begin to explore the experience of dementia (Mills & Bartlett, 2004), and an evidence base is emerging that it may have a beneficial effect in reducing levels of depression (e.g. Cheston, Jones & Gilliard, 2003a).

In therapy with homogenous groups (i.e. those groups made up only of people with a common disability or experience), we can see a number of steps. At first the group forms, principally through the sharing of experiences. Then, as problems become identified as social rather than as personal phenomena, so feelings of isolation are reduced, and feelings of shame and abnormality decline. However: 'the crucial first step is for the group to begin to speak about the taboo topic. As long as this does not happen, the whole group may be stuck and neither those members who belong to the minority grouping nor the rest of the group will have a full voice' (Barnes, Ernst & Hyde, 1999). If they are not addressed, then experiences of shame can have a



Some of Victor's clients were somewhat unnerved by his insistence on complete therapist transparency

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damaging impact on the group's functioning by preventing the group from articulating the taboo topic and thus silencing the group. The emotional atmosphere of a group can be experienced as extremely unsafe – with the shameful act either not being addressed, or being referred to indirectly but never grasped and spoken about.

Many writers (e.g. Alonso & Rutan, 1988; Lynd, 1971) contend that shame can be ameliorated in the group context and that issues around shame need to be addressed in order for the group to have a therapeutic success. There is a consensus that shame can be addressed within groups if the group is experienced as a safe or trustworthy place in which the group can tolerate disclosure of shameful aspects of a group member without punishing (and hence abandoning) him or her. This experience of the group being a safe enough environment in which to explore and express shameful feelings assists in reducing feelings of isolation and lessens the avoidance of closeness and intimacy which is part of the experience of shame. Alternatively, if the group cannot contain and reflect upon shameful experiences in a therapeutic manner, then there is a danger that the group will disintegrate. This creates something of a dilemma for group therapists or conductors: if the group focuses on failures and weaknesses or the other emotional aspects of shame at too early a stage of group development, and before the group is ready, then this will only provoke further, perhaps debilitating, feelings of shame. Sometimes, as a way of resolving this difficulty of approaching shame-filled experiences slowly and gradually, group members may develop indirect methods of communication – for instance, through metaphor (e.g. Cheston, 1996; Cheston, Jones & Gilliard, 2004).

### the group

As part of the Dementia Voice Group Psychotherapy project (Cheston *et al.*, 2003a, 2003b), six groups were established across the southwest of England, each of which lasted for ten weeks. The sessions from one of these groups have been transcribed and analysed (Watkins, Cheston, Jones & Gilliard, 2004). Our analysis focussed on the changes in the way one participant, Robert, accounted for his memory problems over the course of the group, moving from a position at the start of the group where he described

**THE THIEF**

**That relentless thief is slowly  
stealing your memory;  
Yes, and more. Your eyes are being robbed  
of their usual awareness  
And are left with a glassy blank look.  
I see that insidious crook  
as our terrifying enemy,  
For when he's through, you'll only be  
a shell of your former lovable self,  
And we who love you can only watch helplessly  
As he destroys the you that is YOU.  
His name is Alzheimer.**

**Ruth R. Kingsley**

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Association Newsletter (Cleveland, April 1983), and quoted in Gubrium (1986)**

Alzheimer's disease as something that was happening to others, to a point in the seventh session where he described having had a brain scan that showed that his brain had shrunk and that this was 'symptomatic of Alzheimer's disease'. The fourth session of the group was of crucial significance in allowing Robert to develop these new accounts. During the early part of this session Robert twice challenged the group, saying that although people in the group were talking as if they had Alzheimer's disease, he didn't think that anyone in the group had this illness. In response to this challenge group members took turns to acknowledge both that they had Alzheimer's disease, and that they felt either embarrassed or ashamed of this.

Facilitator: [Julie] just said that she feels that she definitely has Alzheimer's.  
Julie: I didn't answer because I was ashamed really.

Facilitator: Chris, you said earlier that you wouldn't tell other people.  
Chris: Yes I think shameful is perhaps the wrong word, it's just that I wouldn't want to publicise it.  
Walter: It's unfortunate that you've got it.

Janet: A lot of people who have been ashamed of it. And for ashamed I mean all sorts of variants on that. And I think it would be a very good thing if there was, because a lot of people are frightened they've got it, or maybe they've been told and then they feel it's shameful. And they, they feel isolated. So I think it's somehow, I don't know what Alzheimer's society policy is, but to make it like having a cold.

The discussion of shame and the fears within the group about having

Alzheimer's disease culminated in Judith, another member of the group describing how she worried about what was to come:

Judith: I just wonder where it's all going to end, that's my fear ....

Janet: *When* it's going to end?

Judith: Where it's going to end, where am I going to end up, just before the end, you know.

Janet: Oh, I see you mean, I talk about death ...

Judith: Yeah.

Janet: to my family and I think the only thing that I'm frightened of is the unknown and that is death to me.

Judith: And after that? Oh, no I'm worried about what comes just before [laughs] it could be years before, couldn't it?

Janet: It could be tomorrow.

Robert: Is it the dying that ...?

Judith: I don't feel that at all, no, because we all go through that, no I'm not frightened about that, no. It's not really my religion to say it at all, but I don't know if there's anything else and I'm not going to worry about that right now, you know.

Facilitator: So what is the frightening, when you say about the future?

Judith: Being, being useless, you know.

Janet: Yes

Judith: Not having all my faculties, I dread that, I dread that, it's as if I'm going to come to it one morning, perhaps, you know and think 'oh my godfathers, what's left?', I really worry about that ... so I'm quite happy in a situation unless I chose to sort of sit there and think. And it's when I think about that, that the curtain comes down.

For Judith, the greatest fear of all was not dying or death itself, but the sense of being 'useless ... not having all my faculties left'. This account is produced after both Robert's challenge, and a series of



participants talking about their feelings around shame. Judith's account is about how a future of deterioration will leave her in years to come – it is a courageous addressing of a powerful emotional issue that until then the group had avoided. Judith also described her own wish to shut down her thinking that's when the curtain comes down'.

As we analysed these interactions we were aware that Robert had listened to this description, as he intervened at one point to ask for clarification ('is it the dying that?'). Central to the sequence of interactions (the first four extracts) which are initiated after Robert challenges the group in the fourth session are the series of voices within the group that articulate a range of emotional reactions to the diagnosis. Until the fourth session, Robert's inability to confront his feelings of shame and fear prevented him from addressing other emotions, such as anger and loss. The key therapeutic factor, arguably, was that the group managed to convey to Robert that shame and fear were experiences shared by the group as a whole. Once the ability of the other group members to articulate their feelings of shame and fear had allowed Robert to confront his own avoidance, so he was able to move through the psychotherapeutic process of assimilation described elsewhere by Stiles and produce more insightful accounts of his position. Thus, while in the first four sessions Robert did not acknowledge that he had Alzheimer's disease, from the fifth session he never again said that he did not have the illness. In the fifth session, Robert angrily accuses the group of mistakenly associating memory loss with a lack of intelligence, but tellingly uses the phrase '... the problem with Alzheimer's as it affects me ....' Then, in the seventh session, Robert again refers to himself as having Alzheimer's disease: 'I've had a CT scan, which was quite an interesting thing in itself, but I got the results back yesterday and it said that my brain had shrunk very, very slightly in the cavity, which is fairly symptomatic of the onset of Alzheimer's. So I asked, 'Well if it's the onset, what happens when you're there' [group laughs], when you're there, and he said 'very little more'. I mean if you got to the point where you couldn't remember anything at all then the brain wouldn't have got any smaller but it's this shrinkage which brings about this symptom of short term

memory loss, which is quite intriguing.'

It is noticeable that although this account is framed in a light-hearted manner, the subject matter of the future for someone living with Alzheimer's is essentially that which Judith had addressed three sessions earlier. Finally, in the ninth session Robert reflected on the changes that had occurred during the group: 'I've got a great deal of moral uplift by coming here. Meeting you, listening to the way you do it. And I don't see the problem now, it frightened me, the problem of declining memory, until I came here, and now I'm not frightened .... Because I thought, well, I'm going mad, I'm going crazy. What am I going to be like in another five years? But now I realize that everybody is getting this problem.'

### summary

This paper has examined the association between shame and insight. I have argued that if shame is not acknowledged and addressed then it can inhibit the development of awareness through two processes. First, given that shame has been identified as a significant part of the experiences of many people diagnosed as having a mental illness, we should not be surprised to encounter it as a powerful emotion within dementia care. Indeed, from this perspective many features of the accounts of people with dementia can be understood as involving the three behaviours most closely associated with shame: namely avoidance, concealment and denial. Each of these behaviours is often seen as arising solely from the effects of neurological impairment rather than, at least in part, a function of the social context. The second way in which shame could be associated with the inhibition of awareness is through its effect as a contagious emotion. As Gilbert has detailed, shame spirals to inhibit both the individual and those around that person from discussing those aspects of living which may be experienced as shameful. There is a collusive avoidance of what in effect becomes a taboo subject. Consequently opportunities to discuss dementia, in particular fears about future dependency and deterioration may be unduly limited. In turn this may inhibit the emotional processing of those problematic and painful experiences around the diagnosis and prognosis of the illness for some people with dementia.

The use of group psychotherapy is one area where individuals with

dementia can begin to address issues of shame. However, access to such groups is the exception rather than the rule. Consequently, one of the many challenges to dementia care services concerns their capacity to create safe-enough containing emotional environments for people with dementia.

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