

Attended dementia: managing the terror of dementia.

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In 2010, the Alzheimer's Society commissioned a poll¹ to find out what people across the country thought and felt about dementia. The results showed that 63% of respondents were frightened about the prospect of growing old and having dementia and that more people were frightened of developing dementia than they were of actually dying. According to the poll, the older participants were, then the more likely they were to be frightened of dementia. Whilst the poll did not sample people who were living with dementia, it does not seem unreasonable to me to assume that many people who have been diagnosed with dementia will continue to be frightened of what is actually happening to them.

As psychologists working in either dementia care or research we need, I believe, to attend to the sheer, bloody awfulness of dementia. Depending on our conceptual inclination we should be interested in how people respond to, defend against, or cope with the threat of dementia. Even when the existential impact of dementia is hard to discern, its shadow is, I believe, always there (Cheston and Christopher, 2019).

Terror Management and Dementia.

In order to explore the psychological impact of dementia, Emily Dodd, Gary Christopher and myself at UWE Bristol have collaborated with Constantine Sedikides and Tim Wildschut from the Centre for Self and Identity at the University of Southampton. We started by looking at whether the social psychological model of mnemonic neglect (Sedikides et al., 2016) might provide a way of understanding why some people living with dementia often seemed to be unaware of their condition. More

¹ YouGov. Are you worried about dementia? Available from: <https://yougov.co.uk/topics/lifestyle/articles-reports/2012/05/22/are-you-worried-about-dementia>

specifically, we wondered whether people might be motivated to forget those aspects of their dementia that they experience as the most threatening. In brief, the mnemonic neglect model suggests that people will be better at recalling information about themselves that is positive and which relates to the central aspects of their self-concept than information which is negative (and thus more threatening). To put this another way, we have a strong tendency to selectively forget negative feedback that relates to the core elements of our identity. This is the Mnemonic Neglect Effect or MNE – a social psychological concept that has similarities to the psychoanalytic defence mechanism of repression. We reasoned that by exploring whether people living with dementia use the MNE to mitigate the distress that they would otherwise experience as a result of knowing about their illness we would be able to explore one of the ways in which people defend themselves against the existential test of dementia.

We hypothesised that the MNE would limit the recall of people who have dementia for the most threatening aspects of the condition and have no effect on their recall of the less threatening aspects. To test this, we first generated a list of over 60 statements about dementia from self-help leaflets designed for people with dementia written either by the Alzheimer's Society or by the National Health Service. We then asked staff and students at the University of the West of England to rate these statements in terms of how threatening they were to their well-being. From their responses we selected the twelve most threatening (e.g., *“As the illness gets worse, so you will increasingly come to rely on others”*) and the twelve least threatening statements (e.g., *“In the illness proteins can gradually build-up inside your brain”*). We split these 24 statements into four groups of six before reading out each group of statements to 62 participants all of whom had had been diagnosed relatively recently with either Alzheimer's disease, vascular, or mixed dementia. Participants were asked to recall as

many statements as they could. Half of the participants had the statements read to them as if they referred directly to themselves, while the other half had them read as if they referred to a hypothetical person called Chris. Our results confirmed our hypothesis: the MNE meant that people with dementia recalled fewer of the most threatening dementia-related statements when these referred to themselves than to Chris. There was no difference in recall of the least threatening statements (Cheston et al., 2018a). What this suggests is that people living with dementia may show a tendency to forget information about themselves and their dementia which is especially threatening to their sense of self.

Given that the MNE acts to protect the self against the anxiety that would otherwise arise from an existential threat such as dementia, then if we bolster the person's sense of self, this should reduce or eliminate the need for the MNE to operate. Acting on this premise we set out to see if it was possible to improve participants' recall of self-threatening information. We did this by drawing on another process that our colleagues in Southampton had previously identified – namely that when people recall a nostalgic (compared to an ordinary memory) then this boosts their psychological resources including self-esteem, social connectedness and their sense that life was meaningful (e.g., Wildschut et al., 2006). A doctoral student I supervised, Sanda Ismail, was able to show that these benefits also applied to people living with dementia (Ismail, 2017). We therefore hypothesised that the psychological benefits that accrued from nostalgia might buffer the self of someone living with dementia to the extent that they would be more able to tolerate the psychological threat that dementia represents and consequently not need to rely on forgetting threatening information to reduce their distress. In other words, people who recalled a nostalgic memory might not subsequently show the MNE for dementia-related information. In order to test this out,

we replicated our initial study, but with two changes. First, we randomised 50 participants with dementia to either recall a nostalgic or an ordinary memory, and secondly, we asked all of the participants to think of the statements as if they applied to them and did not read the Chris-related statements at all. The results confirmed our hypothesis: participants who remembered the nostalgic rather than an ordinary memory then went on to recall significantly more self-referent dementia statements, including the most threatening. Importantly they did this without any increase in their levels of distress (Ismail et al., 2018). Recalling more information had not been upsetting for them.

MNE and clinical experiences.

Until the start of the pandemic, I worked for one morning a week at the RICE memory clinic in Bath often working with couples one of whom had been diagnosed with dementia and offering a space to them to talk about how this was impacting on their lives. Almost invariably the people I meet find it hard to talk about their illness at first. Typically, they may struggle to talk about the diagnosis openly, sometimes forgetting important details or being greatly distressed when they do. Sometimes, the person with dementia may forget that they have been told about their diagnosis, or they might insist that they can still function as they have always done even when being contradicted by their partner. These responses are very similar to the two types of recall errors we found in our experiments: people are more likely to forget about the more threatening aspects of their illness and when they do recall information then they may mis-recall it in such a way that it is less threatening to them.

However, in my clinic I also met many people who were so psychologically resilient that they could openly talk about what they found upsetting about their

dementia. Sometimes, this resilience was always apparent, even when we first met. At other times, the resilience emerged more slowly, and it took several sessions, before they started to feel safe enough to explore their illness with me, adjusting slowly to what was had happened. My experiences in the clinic seem to parallel, I believe, the evidence we have gathered from our more 'laboratory-based' experiments around the MNE. Importantly, both strands of work are concerned with understanding how people defend themselves against the threat of dementia and how this can be mitigated. In so doing, we are coming, I think, to a more nuanced understanding of whether, and how, we can support people living with dementia to adjust to their illness. It is to this issue that I will now turn to reflect on a second aspect of our research work.

Adjusting to the threat of dementia.

If people living with dementia are to be helped to adjust to their illness, then this requires an intervention that can be rolled out on a national basis and delivered by staff who whilst knowing about dementia, may not have had prior experience of delivering psychological interventions. It was for this reason that Ann Marshall and I have produced the Living well with Dementia post-diagnostic course or LivDem (Marshall et al., 2015). The course lasts for eight weeks and is intended to be delivered to 6 to 8 people living with dementia. Additional sessions before and after course involve the person's family or friends, and LivDem is designed to be delivered by nurses, occupational therapists and psychology assistants, albeit ideally with supervision and training from local clinical psychologists. Over the past few years LivDem has proved to be an increasingly popular adjunct to a number of services across the UK as well as in Ireland and Italy. The manual was published in 2019 (Cheston and Marshall, 2019) and last year we launched a website dedicated to the course (www.LivDem.co.uk). LivDem

is not the only way to help people to adjust, and we do not believe that everyone who has been diagnosed with dementia should attend a LivDem course, but it does provide a structured way of helping people to attend to their diagnosis.

So how does the LivDem course help people to adjust to their diagnosis? Well, I suspect that the LivDem course contains a number of elements that reduce the extent to which people feel threatened by dementia. First, the structured nature of the course encourages participants to distance themselves from the dementia (Cheston, 2013) and enables them to talk at their own pace. In the initial sessions, facilitators encourage the group to talk about their symptoms, then in subsequent sessions ask about the emotions associated with memory loss before turning to how people cope with these feelings including who they talk to. It is not until week six that the group are asked to talk directly about their diagnosis. As a consequence, participants do not feel forced to talk about something that they would prefer not to. Secondly, there is the sense of universality that people get from meeting others in their position, talking about what is happening and as a consequence realising that they are not on their own. In our work on nostalgia, we found that its impact on the recall of threatening information about dementia was mediated by the extent to which nostalgia produced feelings of social connectedness (Ismail et al., 2018), and it may well be that the impact of LivDem is also mediated by a similar sense of sociality. Finally, by exploring and sharing distressing emotional experiences including shame (Watkins et al., 2006) and loss of control (Cheston, 2015), so LivDem encourages the assimilation of the most problematic aspects of dementia (Cheston et al., 2017, 2018b). Adjustment is inherently an emotional experience – and as psychologists we do not attend to this aspect of dementia at our peril.

Looking at (and away from) the sun.

In one of my early encounters with existential psychology I came across Irvin Yalom's book *Staring at the Sun: Overcoming the Terror of Death* (Yalom, 2008). The central conceit within the book is that looking at our own death is much like looking at the sun – both are too powerful for us to look at directly for any length of time. Instead, we shade our eyes or glimpse them indirectly, obscured by clouds or being aware at the shadows they cast. We know that death and the sun are both present in our lives, but for most of the time we are unaware of them. We know about our own mortality, but we also chose not to know. A life lived constantly in the full glare of death might be overwhelming, so we look away.

It is the same, I believe, with dementia. The people I work with look at their dementia and then look away. They both know about dementia, but also do not know. This is the case in the clinic or in LivDem groups, where people approach, and then retreat from their dementia. Knowing that you can retreat from something gives you the courage to go closer. We found this in our experimental work: selective forgetting allows people living with dementia to filter out its more threatening aspects. I sometimes also wonder whether something similar can occur within dementia services – sometimes it may be easier to frame dementia as a condition that it is possible to live well with, than to stay with its awfulness. If we now recognise that a diagnosis of dementia brings the possibility of hope, then we must also remember that it also inherently brings threat. Importantly, by being prepared to explicitly recognise this aspect of the lived reality of dementia for our clients, we can bear witness to the way in which they manage the existential threat it represents. Only by doing this can we fully attend to dementia.

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